



Steps to Healthier Living™

Positive Self-Management Program

*An Evidence-Based Workshop
Originally Developed at Stanford University*

LEADER'S MANUAL

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Steps to Healthier Living™

The Positive Self-Management Program

*An Evidence-Based Self-Management Workshop
Originally Developed at Stanford University*

LEADER'S MANUAL

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The Positive Self-Management Program (PSMP) was developed at Stanford University. The primary developers of the program are Allen Gifford, M.D. (now at Boston University and the Veterans Administration Medical Center, Boston); Kate Lorig, DrPH, Virginia González, MPH, and Diana Laurent, MPH, while at Stanford. The program was modeled after a previous Stanford self-management program for people living with any chronic conditions (the Chronic Disease Self-Management Program/CDSMP).

Several assumptions underlie the PSMP:

- People with similar chronic conditions such as HIV have similar concerns and problems.
- People with HIV must deal not only with their disease, but also with the impact it has on their lives and emotions.
- Peers with HIV, when given training and a detailed Leader manual, can facilitate the PSMP as effectively as health professionals.
- The process or way the PSMP is presented is as important, if not more important, than the subject matter.

The PSMP was first offered in the San Francisco community as a pilot study through Dr. Gifford and the Stanford Patient Education Research Center in 1994. A second pilot study was conducted by Kaiser Permanente at their Oakland and San Francisco Medical Centers in 1995.

Study of the PSMP was based in part on the successful results of a previous five year research project of the CDSMP, where it was found that people who took the program, when compared to people who did not take the program, improved their healthful behaviors (exercise, cognitive symptom management, coping, and communications with physicians), improved their health status (self-reported health, fatigue, disability, social/role activities, and health distress), and decreased their days in the hospital.

While at Stanford University, Dr. Allen Gifford received a grant from the Robert Wood Johnson Foundation to develop and pilot a community-based self-management program to assist people with HIV. The study was completed in 1997. Participants

who took the PSMP were found to have improvements in their symptoms in the original developmental study. More recently, we found that HIV patients in PSMP who are using antiretroviral medications have significantly better medication adherence and have better HIV suppression in the blood after 6 months. Despite this, they have no more side effects than non-PSMP participants.

Full information about the published results for the Stanford Self-Management Programs can be found in Appendix VIII.

The Positive Self-Management Program is designed to be used with the book *Living a Healthy Life with HIV*, by Allison Webel, Kate Lorig, Diana Laurent, Virginia González, Allen Gifford, David Sobel and Marian Minor. Books can be ordered from Bull Publishing Company, P.O. Box 1377, Boulder CO 80306, phone 1-800-676-2855. Bull Publishing also distributes audio CDs designed for use with the relaxation exercises in this workshop. Order forms for books and CDs can be found on Bull's web site (<http://www.bullpub.com>).

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Checklist for Leaders

- Post the agenda at the beginning of every session.
- Keep to the time limits for each activity in the workshop.
- Have each participant make an Action Plan in every session and give feedback in Sessions 2-6. DO NOT SKIP THESE.
- If people are reluctant to participate in activities, gently encourage but do NOT force their participation.
- Remember to MODEL appropriately, especially in making an Action Plan and giving feedback, by always starting with yourself.
- Do not talk about yourself for more than one minute when using personal examples.
- Encourage workshop participants to examine their own experiences and to share these with the group.
- Monitor sharing to prevent individual monopoly.
- Keep sharing directed toward the subject.
- Problems should be addressed by the group first (i.e., brainstorm solutions).
- Reinforce verbally or non-verbally (with nods of head, etc.) every person, every session.
- If someone misses a session, call to determine the problem (be careful not to ask yes/no questions).
- Do NOT add anything to the workshop and do NOT bring in outside speakers!
- If you have questions or problems, notify your program coordinator.

Purpose

- To introduce the group members to each other
- To inform the group about the general principles of HIV self-management
- To identify how their role and that of the healthcare providers differ when dealing with HIV and an acute condition
- To identify group members' problems caused by HIV
- To emphasize the fact that people living with HIV share many of the same problems
- To introduce HIV self-management techniques
- To introduce the mind-body connection and the mind as a powerful self-management tool
- To provide practice with distraction
- To provide basic information about monitoring HIV
- To introduce **action plans** as a key self-management tool

Objectives

By the end of this session, the group members will be able to:

1. Describe their role in the care of HIV
2. Identify a set of problems that are common among people with HIV
3. Name at least 2 components of the HIV Self-Management Tool Box
4. Practice distraction as a self-management tool
5. Define CD4, T-cell, and viral load tests
6. Make a self-management action plan for the coming week

Materials

- Workshop Overview/Homework handout for each participant
- Charts:
 - 1: HIV Self-Management Tasks
 - 2: HIV Self-Management Tool Box (**post at all sessions**)
 - 3: Guidelines (**post at all sessions**)
 - 4: Brainstorming (**post at all sessions**)
 - 5: HIV Monitoring Tests
 - 6: Parts of an Action Plan (**post at all sessions**)

- Blank name tags for everyone (*These should be reusable, as you will need them every week.*)
- Flipchart/easel
- *Living a Healthy Life with HIV* book for each **household** (if people want extra books, they can be purchased through Bull Publishing)
- Blank chart pad/felt pens or blackboard chalk
- Pad of paper, extra pencils
- Kleenex tissues
- **A watch or other timing device that marks seconds**

Homework Assignments Given During Session 1

- Please think of something in your life for which you need to make a decision and have it ready for next week's activity.
- During the week carry out your action plan and note if there are any challenges and how you overcame them.
- Reading: *Living a Healthy Life with HIV*, Chapters 1 and 2, pages 88-90, 171-172, 175-178.

Reading for Leaders' Preparation

- *Living a Healthy Life with HIV*: as homework assignment, above
- Action Plan Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of each meeting:

Session One Agenda

- Activity 1: Introduction to Workshop (20 minutes)
- Activity 2: Group Introductions (30 minutes)
- BREAK (20 minutes)
- Activity 3: The Mind-Body Connection/Distracted (20 minutes)
- Activity 4: Monitoring HIV (10 minutes)
- Activity 5: Introduction to Action Plans (40 minutes)
- Activity 6: Closing (10 minutes)

Activity 1

INTRODUCTION TO THE WORKSHOP

20 minutes

Materials:

- Chart 1, “HIV Self-Management Tasks”
- Chart 2, “HIV Self-Management Tool Box”
- Chart 3, “Guidelines”
- Workshop Overview/Homework handout

Note to Leaders: Charts for this workshop are shown in boxes throughout this manual. The material printed in the boxes *in italics* may be added verbally and should **not** be printed on the charts. Only the material printed **in bold** needs to be printed on the charts. **Make your charts from the Chart Summary in the Appendix, NOT from the manual text.**

1. **Instructions to Leaders:** As participants arrive, distribute name tags. Have them write their names as they like to be called (first name or nickname, not last name). These should be large enough so that they can be read across the room. Felt pens are good for this. **Do NOT make name tags for them!** (This is a self-management workshop.) Also, give them the Workshop Overview handout.
2. **Say in your own words:** Hello and welcome to the [NAME of your workshop]. I’m [FIRST NAME] and this is [FIRST NAME]. We will be the facilitators for this workshop over the next six weeks. Like all of you, we are here because we either live with HIV or we live with or are close to someone who does.
 - a. Having HIV can be frightening, frustrating and angering at times. But to live well with HIV we need to learn to balance our fears and our anger with all the opportunities of life that are open to us.
 - b. With the range of medications available, HIV is now considered a long-term or chronic condition, just like asthma, arthritis, diabetes, and so many others. Learning to manage our condition has always been important for people living with HIV, and it has become even more important now that we are living longer, often healthier, lives than ever before.
 - c. We believe in this program, so we took training through [NAME of organization] to become facilitators.

- d. Now, before we get started, we'd like to mention a few "housekeeping" items and also assure you that everything here is completely confidential. **What is said in the group stays in the group.** We will be going through more guidelines shortly. First, please turn off your cell phones and other devices, or put them on silent.

Instructions to Leaders: Mention those that apply to your site, such as location of restrooms, parking etc.

3. **Say in your own words:** Before we all introduce ourselves, we will give a short introduction and set the ground rules. We'd like to emphasize that we are all here because we want to learn how to better manage HIV.
- a. To do this, it is important to understand that, when dealing with any long term physical or mental health condition, both the health provider's role and ours is different than when treating acute health problems such as the flu, an infection, or something more serious like an episode of pneumonia or other "opportunistic" infections.
 - b. With acute conditions, the causes, diagnoses, tests and treatments are usually pretty clear cut. The health provider chooses what to do and we follow their orders.
 - c. With chronic or long-term conditions such as HIV, however, things can be more complicated and uncertain.
 - d. Chronic conditions also tend to change over time, so the role of the provider becomes one of teacher and adviser while we become partners, responsible for managing our condition on a daily basis and informing the provider of our treatment preferences.
4. **Say in your own words:** No matter what we do, though, we are **managing** our lives with HIV every day. Most of the time we spend dealing with our health condition is not spent in the provider's office. How we live everyday affects our symptoms, our health and our quality of life.
- a. For example, we may choose to do nothing and gradually lose the ability to do the things we want, or we can work on improving or maintaining our overall fitness in order to maintain or regain the things we enjoy doing.

- b. Our choice is whether to be a passive manager or an active manager. If the choice is to actively manage, then we must be willing to take on 3 HIV self-management tasks:

Chart 1

HIV Self-Management Tasks

Take care of health condition

- *(Such as taking medicine, exercising, going to our health care providers, eating well, getting help when it is needed)*
- *(Keeping informed about our condition - asking questions, reading, and so on, and, when necessary, carrying information from one provider to another)*
- *(Taking part in planning our treatment program by monitoring and reporting on our condition, sharing our preferences and goals with the doctor and all other members of the health care team, and learning to use online or digital tools to manage your health and communicate with your providers)*

Carry out normal activities

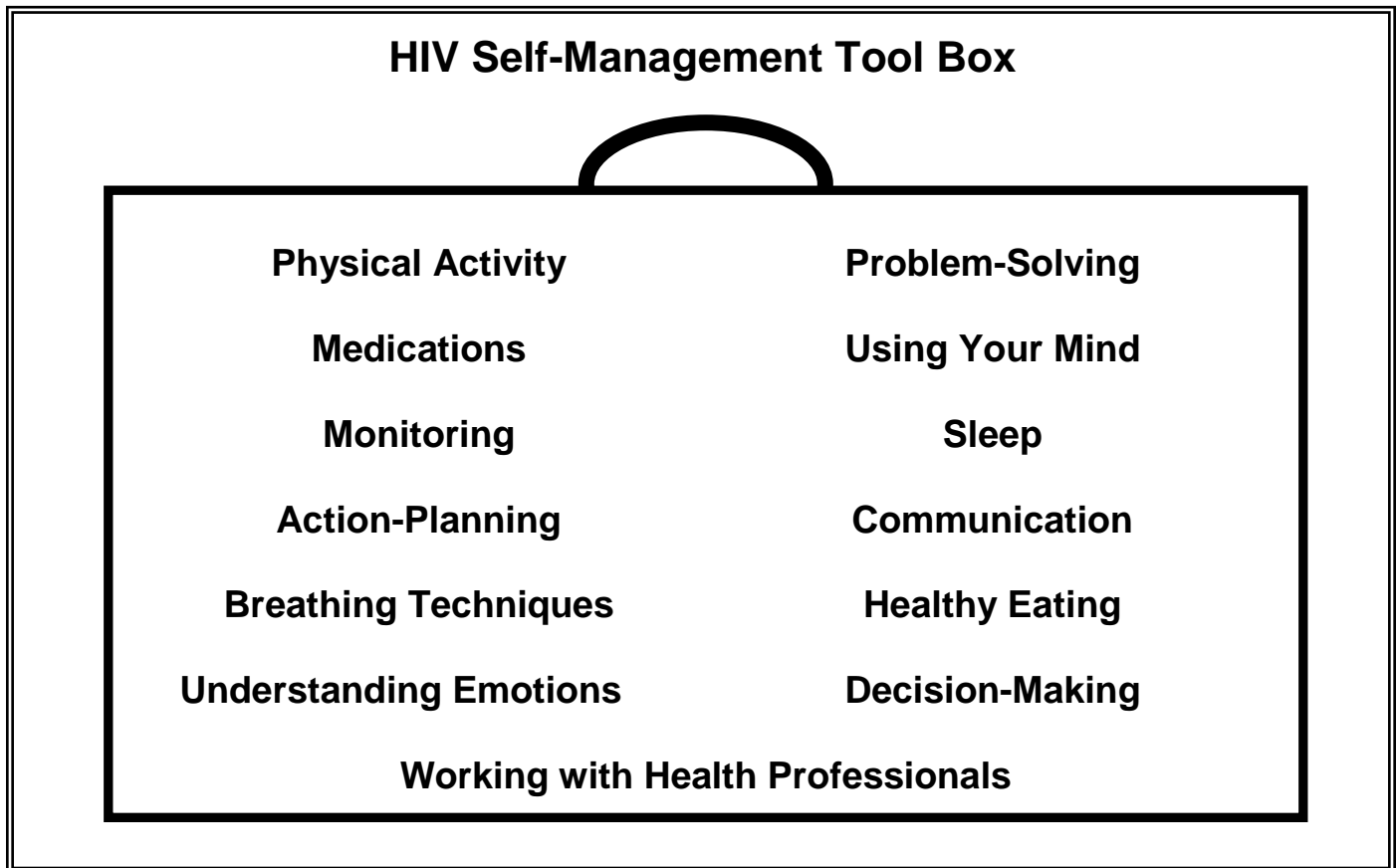
- *(Such as household chores, employment, social life)*
- *(Doing the things in life that we like and that are important to us. This may mean changing the way we do things. For example, having prepared dinners in the freezer for times we are not feeling up to cooking)*

Manage emotional changes

- *(Changes brought about by our illness - such as anger, uncertainty about the future, changed expectations and goals, and sometimes depression)*
- *(Changes can also happen in our relationships with family and friends)*
- *(Knowing that there will be emotional “ups and downs,” and that the “downs” are not pits to crawl out of, but natural ups and downs that we all have in life)*

5. **Say in your own words, pointing at Chart 2:** This workshop is designed to give us some of the self-management tools needed to take on these tasks, and help us to become more active self-managers. This in turn can greatly improve our lives. These include:

Chart 2



6. **Say in your own words:** During this workshop we will have the opportunity to practice using these different tools. Your handout shows when we will be covering each topic during the next 6 weeks.
- This is a very interactive workshop. All of us will be practicing what we learn and what we have already learned from experience.
 - You will also notice that on the back of the handout there are weekly homework assignments. They are to help you build your skills, practice and reinforce the lessons of the week or to prepare for the next week's lessons.

Unlike school, this homework is for you. We will not look at or grade your homework. However, in many cases you will be reporting in class about what you have done and what you have learned.

- c. Although we can't cover all the subjects we would like to during this workshop, such as aging with HIV, women with HIV, medication specifics, and so on, the book, *Living a Healthy Life with HIV*, has a wealth of information beyond what we cover in the workshop.
7. **Say in your own words:** Also, in order to benefit from this workshop, there are other responsibilities each of us in the group must be willing to do. These are:

Chart 3

Guidelines

1. **Come to every session** (*and be on time*)
2. **Be respectful of others and their ideas** (*don't talk over or interrupt others; allow everyone a chance to talk; it's ok to disagree*)
3. **Maintain confidentiality** (*personal information shared in the group stays here in the group*)
4. **Give any new activities at least a two-week trial** (*before deciding which tools work best for you*)
5. **Make and complete a weekly action plan** (*we will be talking more about this at the end of this session*)
6. **Turn off your cell phones and other electronic devices**

Instruction to Leaders: Add any other items that apply to your group (such as please do not wear heavy perfume, no selling of products, take care of your personal needs)

Activity 2

GROUP INTRODUCTIONS

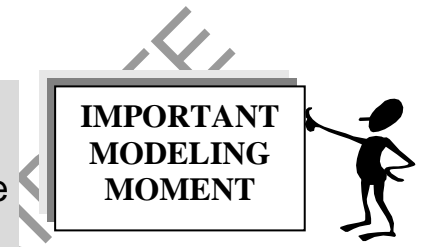
30 minutes

Materials:

- None

1. **Say in your own words:** Now we will all be introducing ourselves, stating how long we have been affected by HIV, if we wish, and what problems this has caused us in our lives. How does HIV affect our lives?

2. **Instructions to Leaders:** Introduce yourself first. Be careful here as you will be modeling how the participants will introduce themselves. (Modeling will be important for every activity you do. Leaders should always model the activity before asking the participant to do so.) Do not dwell on your specific problem(s). In your introduction:



- State how long you have been diagnosed with HIV, or how long someone close to you has.
- Name one or two problems that living with HIV has caused you, or that you have experienced as a result of living with someone with HIV. How does living with or being close to someone with HIV affect your life? (Do not list symptoms, but what problems those symptoms cause you.)
- Leaders should take care that they do not relate experiences of others, only of their own experiences

The introduction might be something like this: *"I'm Jane and I was diagnosed with HIV five years ago. Having HIV has meant slowing down and never being sure how I will feel day to day."* Or, *"I'm Juan and I have lived with someone with HIV for three years. The problems this causes me are the fear of losing him and not knowing when offering help is appropriate."*

The Leader not facilitating this activity should write the first leader's problems on the board or chart pad, then introduce themselves and write their problems.

3. **Say in your own words:** Now we would like to go around the room and have you introduce yourselves. Because we have limited time, please be brief in your

introduction. What we would like to hear from you is:

- a. Your first name or nickname
- b. How long you have been diagnosed with HIV, or if you are close to someone with HIV, if you don't mind saying
- c. Then give us one or two problems that living with HIV causes you. How does it affect your life on a day-to-day basis? For example, not being able to do what you want to do, not knowing what to expect or not able to take your medications all the time.
- d. If you do not have HIV, then tell us one or two problems that affect **YOU** because of living with someone who does
- e. Do we have a volunteer to start? After the first person, we'll go around the room.

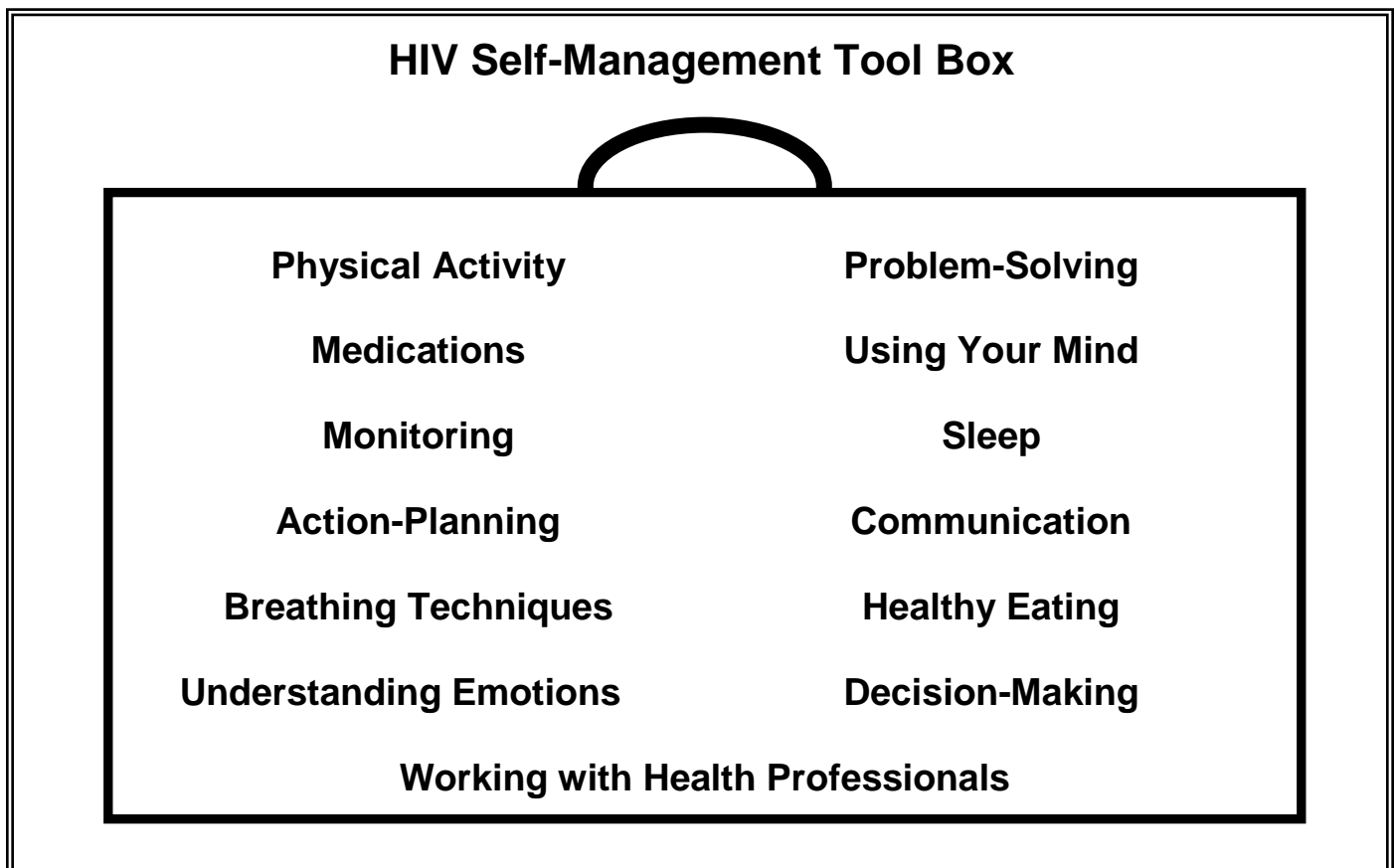
4. **Instructions to Leaders:** The other Leader should list what people say on the board or chart pad. Put a check mark next to a word or statement every time it is repeated by another person.

If people start to tell a story or go on and on, redirect them to just state how long they have been affected and one or two problems that they have.

If people just name symptoms, redirect them: "and how does that fatigue affect your life?"

(Continued on the next page)

Chart 2



5. **Instructions to Leaders:** After they all have shared, be sure to point out that many of their concerns are similar and we will be addressing most of them with the HIV Self-Management Tool Box (Chart 2).

Be specific, if possible, pointing at the tools in the Tool Box (Chart 2) that will help some of the specific problems listed, such as “Some of you said you can’t do what you used to do.” Others mentioned emotional and communication issues. We’ll be learning some tools that might help, such as Problem-Solving, increasing Physical Activity, Dealing with Difficult Emotions, and Communication Skills”.

Tell the group that we will be sharing more about these problems and using many of the tools from our HIV Self-Management Tool Box to deal better with them throughout the next six weeks.

6. **Say in your own words:** There are some subjects during this workshop that may be new to some of you, but others already may be knowledgeable about some of the specifics about HIV. For those, please consider it a brief review. We will be covering even more subjects that are about self-management of any chronic condition, not just HIV.

7. **Say in your own words:** Let's take a break for 20 minutes and when we come back, we will start learning about some of the tools in the Tool Box



BREAK

20 minutes

Activity 3

20 minutes

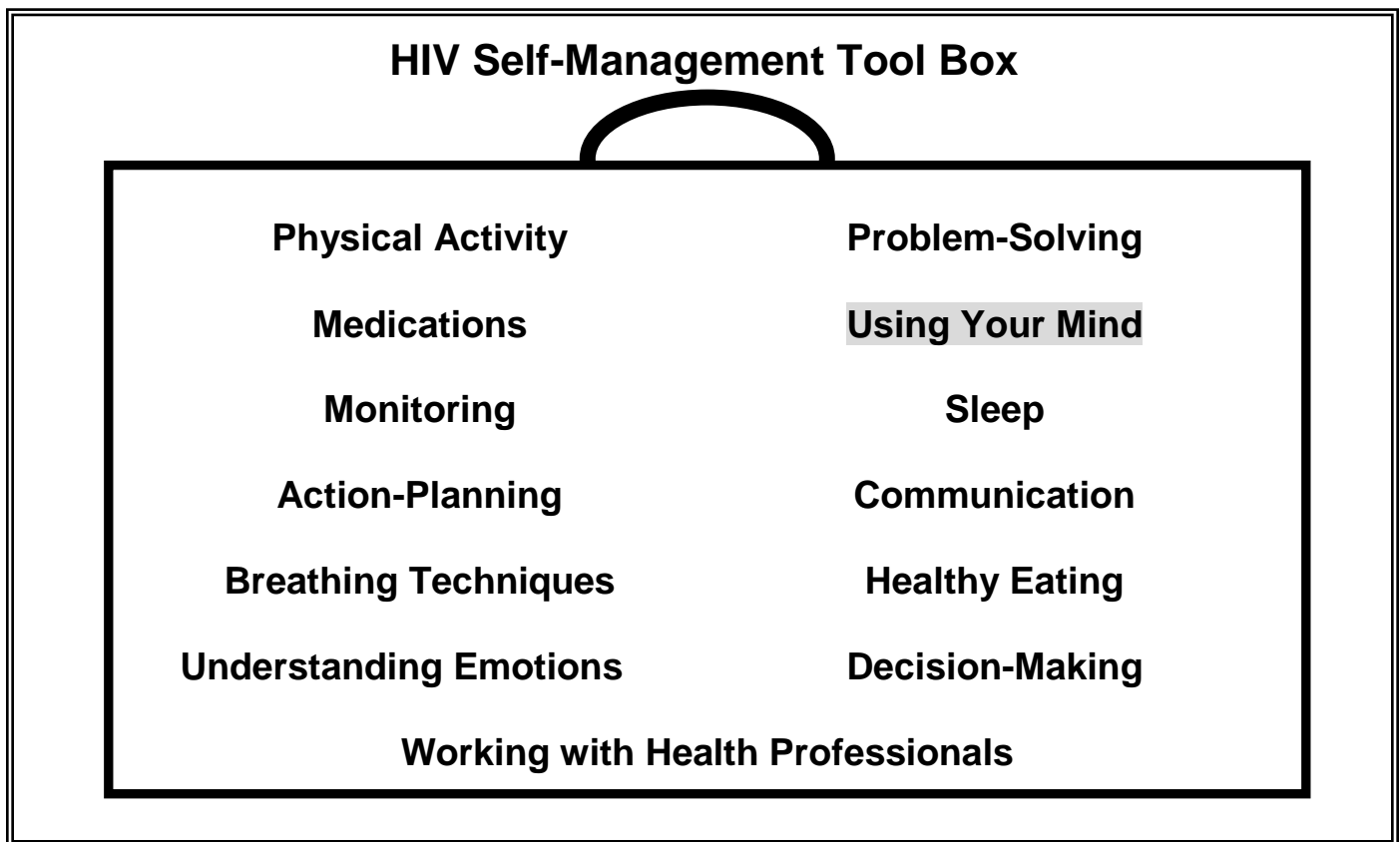
THE MIND-BODY CONNECTION/ DISTRACTION

Materials

- Chart 2, "HIV Self-Management Tool Box"
- Chart 4, "Brainstorming"

1. **Say in your own words, using Chart 2, pointing to "Using your Mind" as you mention it:** We've all heard about the connection between the mind and body. We know that our mind can have an important influence over our body.
 - a. In this workshop, we're going to look more closely at this relationship, as we explore ways to manage our health problems, and especially the symptoms we experience, both physical and emotional.
 - b. Right now we are going to start with a look at thinking activities. These are techniques that involve using our minds to manage symptoms and help us feel better.

(Chart 2 on the next page)



2. **Say in your own words:** One of our self-managers once said, “mind over matter and mind matters”. For sure the mind is a very powerful tool.

To demonstrate how your mind can affect your body, we’re going to do a short visualization activity. So, please relax and, if comfortable, close your eyes.

3. **Say and talk slowly:** Imagine you’re holding a big, bright, yellow slice of lemon. Picture it in your mind. You can feel the texture of the lemon rind in your hand. . . [Pause] . . . Now lift the lemon to your nose. You can smell its strong, citrus aroma.

[Instructions to Leaders: PAUSE to let them imagine it]

...Next, bring the lemon slice to your mouth and take a big bite out of the lemon...its juicy... the juice squirts all through your mouth... you can taste the tart lemon juice filling your mouth...the juice dribbles down your chin... Taste the juice from that lemon!

[Instructions to Leaders: Give participants a few seconds to imagine this, then tell them to open their eyes.]



4. **Say:** What happened to your body while you were imagining the lemon juice in your mouth?
- Instructions to Leaders:** Point out that the salivation and puckering they experienced is caused by the mind - there is no lemon present.
 - Say in your own words:** This is a simple example of how the mind can affect the body with very little effort. Just imagine what we could do if we learned ways to use that power to help us with our symptoms!
5. **Say in your own words:** In this workshop, we will learn several of these thinking type techniques. Our job is to try the different methods and find the ones that work best for us. Most people find that they like some techniques better than others.
- We will be learning 3 thinking type activities in this workshop: distraction, relaxation body scan, and positive thinking.
 - Equally powerful and helpful to many people are prayer and meditation, which not only help the mind and body, but also the spirit. If prayer and meditation are important in your life, we encourage you to continue to use them.
 - There are also many other activities for using the mind that you may wish to research for yourselves, some of these are discussed in the *Living a Healthy Life with HIV* book.
 - Caution:** None of these techniques should be used to overcome chest pain or sudden numbness or weakness on one side of the body. These are warning signs of possible heart attack and stroke and should be immediately reported. They need medical management.
6. **Say in your own words:** Today we're going to practice **short-term distraction** to help us manage our symptoms.
- It's difficult for the mind to focus well on two things at once. Our minds are like a radio. While a radio can get many stations, only one station at a time comes in well.
 - This is also true for the mind that has many thoughts but can really only focus well on one thought at a time. Therefore, learning how to use distraction can be beneficial in managing symptoms. Let's look at this technique more closely.

7. **Say in your own words:** Distraction is especially good to use when we have to do short activities that cause us trouble such as pain and discomfort or anxiety. Examples are climbing the stairs or doing some routine chore, sitting in a dentist's chair, having blood taken.
- Short-term distraction can also help us when we have troubling thoughts, trouble falling asleep, getting back to sleep after waking up during the night, or even when we experience shortness of breath.
 - Because the mind doesn't focus well on two things at the same time, we force our mind to think about something other than the symptom, so the symptom will feel less intense.
 - Again, do not practice distraction or ignore a symptom when you are experiencing chest pain or sudden numbness or weakness on one side of the body.**
8. **Say in your own words:** Some examples of short-term distraction techniques are counting backwards by threes, playing a baseball game in your head, thinking of a flower or bird for each letter of the alphabet, making plans for a future event, or trying to think of all of the words in an old song. All of these are done only in your head.
9. **Say in your own words, pointing to Chart 4:** We're going to do a “**brainstorm**” next. The purpose of brainstorming is to allow us to share as many ideas about a topic as possible in the quickest way possible. To do this, we'll be following these guidelines.

Chart 4

Brainstorming

- **Anyone can share**
- **No commenting during brainstorm** (*about others' ideas, negative or positive*)
- **No questions until after** (*the brainstorm*)
- **Clarification waits until after** (*when all the ideas are out, we'll go over anything that needs clarification*)

Brainstorming Guidelines for Leaders

- The facilitator reads the question as written in the manual.
- The scribe writes the brainstorm question, using KEY words.
- The facilitator repeats the ideas loudly, using the participant's own KEY words while looking at group, not at the scribe.
- If the idea is too long, ask the participant to shorten it. If they cannot, ask for permission from them if you shorten or rephrase it.
- The scribe listens only to the co-Leader and writes what the facilitator says.
- The scribe does not use abbreviations or symbols.
- The scribe is responsible for telling the facilitator if they can't keep up with the ideas.
- The facilitator controls the "traffic"- slowing the brainstorm if the scribe needs to catch up.
- Neither the facilitator nor the scribe comment or allow anyone else to comment on the ideas (positively or negatively, verbally or by facial expression).
- The facilitator does not allow questions until after the brainstorm is over.
- If there are fewer than 15 ideas, the facilitator uses silence **...W...A...I...T...!** (it's not over until you have counted to 15 to yourself with no new ideas). If there are no more, the brainstorm is over.
- The facilitator does NOT call on people.
- The scribe tells the facilitator when there are 15 ideas listed.
- If there are 15 ideas, the facilitator tells the group you will take 2 more and end the brainstorm.
- After the brainstorm, the scribe or facilitator reads back the list to the group.
- The facilitator asks if any ideas need clarification.
- If there are ideas listed in the manual to add, the facilitator adds only those ideas that are not already listed.
- If any ideas are "inappropriate", such as alcohol or violence, the facilitator points this out politely without pointing anyone out.

10. **Say:** The question we're going to brainstorm is:

What are some other distraction techniques?



a. **Instructions to Leaders:** After the brainstorm, read back the list, ask for clarification, and point out the differences between the types of distraction people may have listed.

These include distractions that use thoughts for the **mind** to focus and concentrate on, such as counting backwards by threes, thinking of a flower or bird for each letter of the alphabet, or trying to think of all of the words in an old song, versus those that are **physical activities** we engage in, such as reading, going shopping, talking to friends, or watching television.

b. **Say in your own words:** Both types of distraction are good strategies for helping us manage our symptoms, but right now we're talking about the "thinking" type of distraction, a technique that uses only the mind for short periods of time.

11. **Say in your own words:** Now we're going to try a distraction activity. First, we want you to concentrate on your pain or discomfort for a short time, and then rate your pain or discomfort on a scale of 0-5 (5 being most painful). If you don't have pain, you can pinch yourself to produce a little pain or irritation, or make a tight fist to create muscle tension. You can do anything that will not cause harm but will cause a little discomfort.

a. **Instructions to Leaders:** Tell them to start. Time this for 30 seconds but do **not** tell them how long they will do this!

b. **Say in your own words:** Now rate the pain or discomfort you just experienced on a scale of 0-5 (5 being most painful) and remember it.

c. **Say in your own words:** Now we're going to do the same thing while using a distraction technique. Take a moment to think about what distraction technique you are going to use. It can be one of our examples from before, such as playing a game in your head, counting backwards, or thinking of a flower for each letter of the alphabet.

d. **Instructions to Leaders:** Pause to give participants time to choose a distraction technique.

e. **Say in your own words:** If you have been pinching yourself or making a fist to produce discomfort, please continue with that. If you are already experiencing

pain or discomfort, you don't need to try to produce more. OK, now start thinking of your distraction. Begin.

f. **Instructions to Leaders: Time this for 45 seconds. Do NOT tell them how much time you are having them do this.**

g. **Say in your own words:** Now rate the pain or discomfort you just experienced on a scale of 0-5 (5 being most painful) and remember it.

1. By show of hands, how many of you felt a difference?
2. Which time was more painful or uncomfortable?
3. Did both times feel about the same length or did one time seem longer?



h. **Instructions to Leaders:** Point out that the distraction helped them to think the second time was shorter or the same as the first, although it was actually 15 seconds longer.

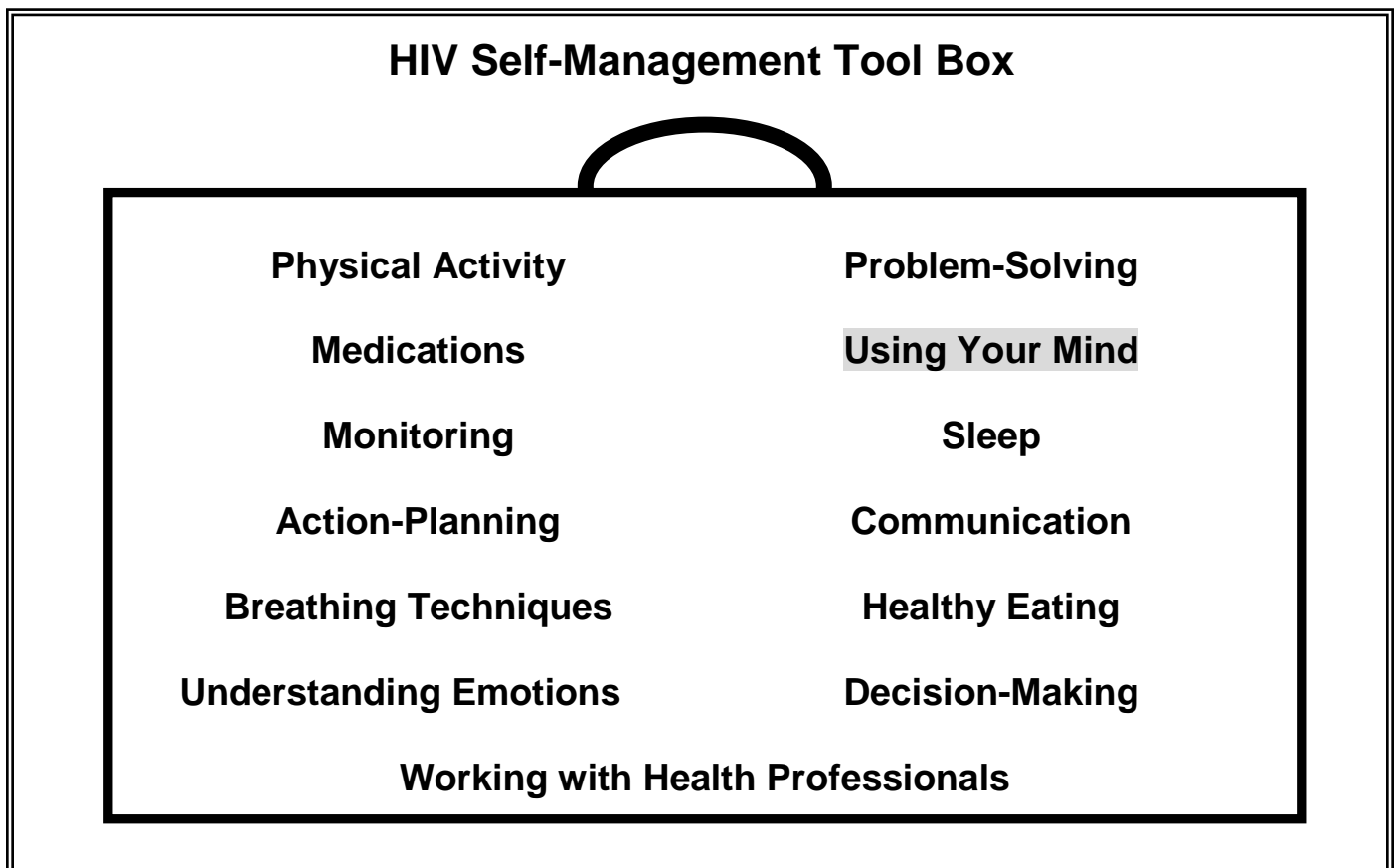
12. **Say in your own words:** Remember, using distracting thoughts are best for short periods, whereas engaging in physical activities that provide a diversion work for longer periods.

- a. When you engage in an interesting activity, such as going to a movie, gardening, reading, and so on, you forget about the symptoms.
- b. However, sometimes you may need to interrupt a long, distracting activity so as not to overdo and cause more symptoms later.

17 **Say in your own words, pointing to “Using Your Mind” on Chart 2:** Remember, “Using Your Mind” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



Activity 4

10 minutes

MONITORING HIV

Materials

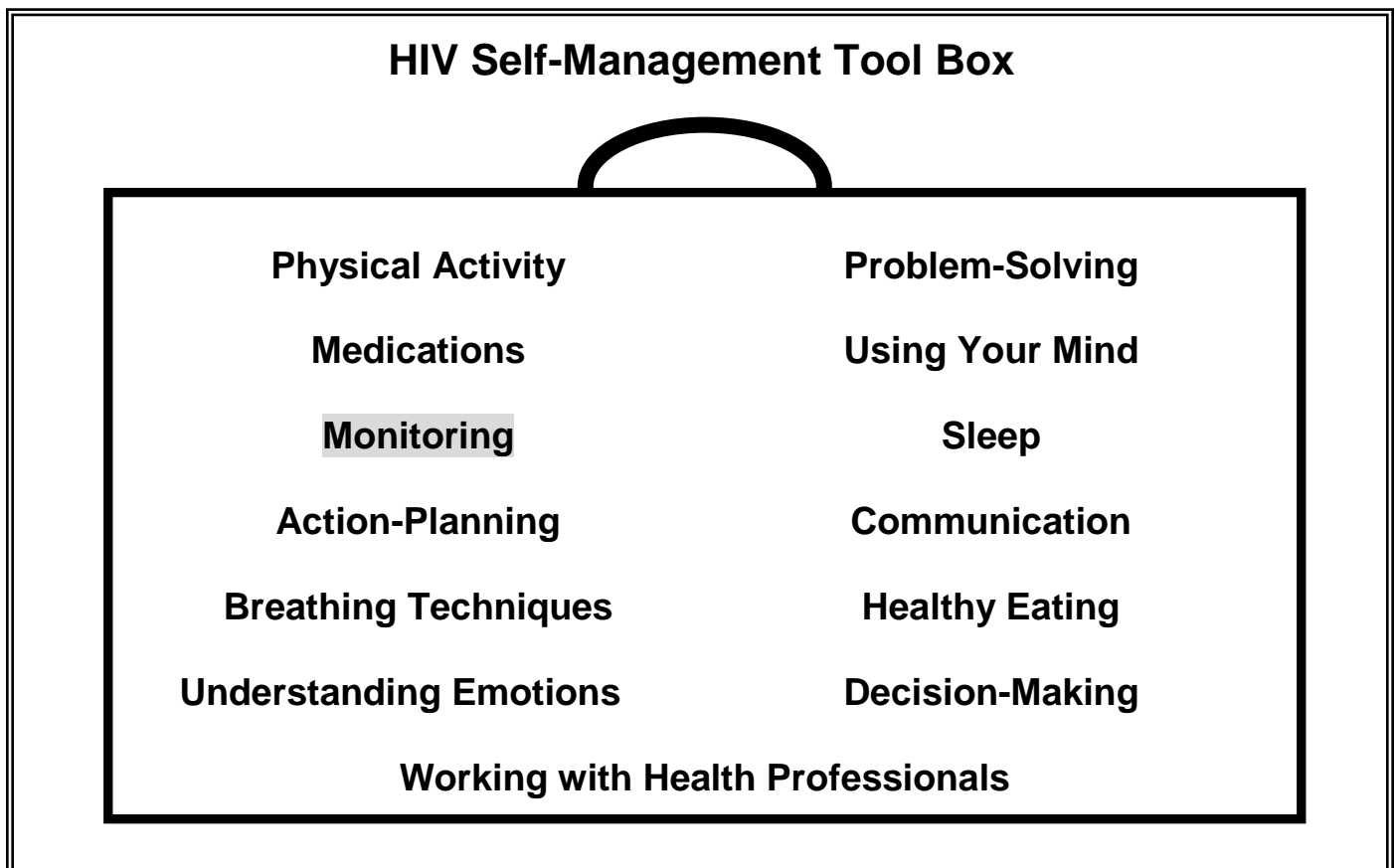
- Chart 2, "HIV Self-Management Tool Box"
- Chart 5, "HIV Monitoring Tests"

1. **Say in your own words, pointing to Monitoring on Chart 2:** One of the first tools we will learn about that is important to managing HIV is monitoring. This involves taking two important blood tests to measure your HIV and what they mean.

As HIV self-managers, it is our responsibility to know the general guidelines for these tests and to make sure that they get done on a timetable we establish with our health care provider.

(Chart 2 on the next page)

Chart 2



2. **Say in your own words:** Unlike many other viruses, HIV is sneaky. It actually invades and destroys the very cells in our blood that fight infections. Without healthy immune-fighting cells, we can't fight off other infections.
3. **Say in your own words:** Monitoring and treating HIV infection can be challenging for both the person with HIV and the health care team. Now let's look at some of the tests our health providers use to monitor HIV infection.
4. **Say in your own words, pointing to Chart 5:** The two main tests for people living with HIV are **T-cell**, also known as **CD4 count**, and **Viral Load**. These tests are done regularly on a schedule your doctor sets with you.

Generally, the CD4 count is done every 3-6 months during the first two years of treatment or while the count is less than 300. After that, the CD4 count is done every two years if the viral load is suppressed. However, if the CD4 count is between 300 and 500 the test is done every 12 months.

The viral load is the main test now and this should be checked every 3-6 months.

HIV Monitoring Tests

T-Cell or CD4 count (*measures how well your immune system is coping. T-cells help you stay healthy by fighting off infections. T-cells are what the HIV virus takes over and destroys over time.*)

- **500-1800 – normal**
- **200-500 – weakened immune system**
- **Below 200 – danger of opportunistic infections**

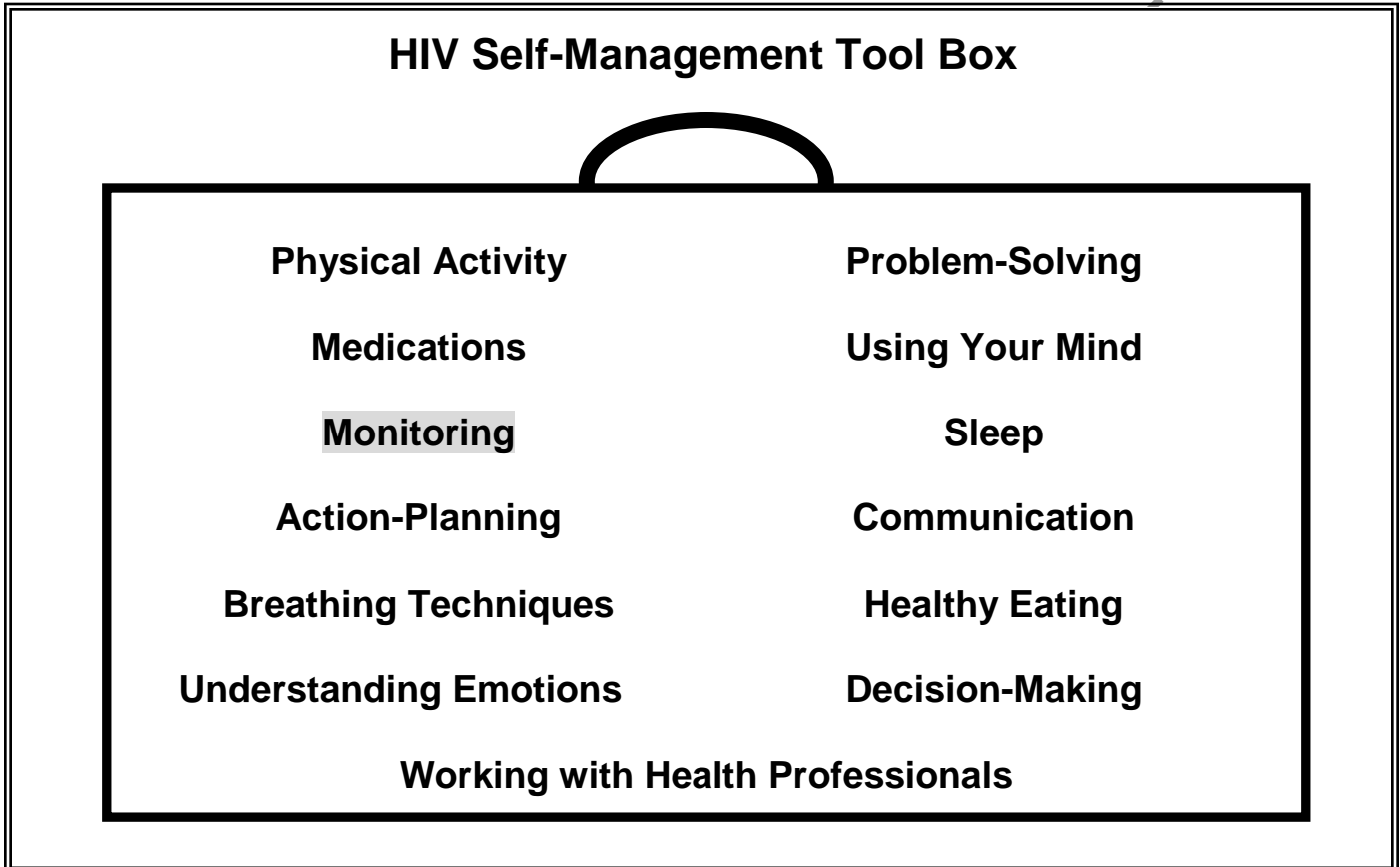
Viral Load (*measures how much HIV virus is in your blood. Low viral load means that HIV is less likely to damage your immune system and you are less likely to get an opportunistic infection or to give the virus to someone else. The numbers can range widely. These are “ballpark” numbers. Your health care team or clinic may use different numbers. A person needs to have an undetectable viral load for 6 months to be considered undetectable.*)

- **Under 40-50 – undetectable**
- **Fewer than 10,000-30,000 – low but detectable**
- **About 100,000 – high**
- **Over 1,000,000 – very high**

- a. The results of these tests are used by your health care provider to determine how your body is doing in fighting the infection.
- b. They help you and your health care providers decide when to start medications and when to change or adjust medications.
- c. The tests also measure the effectiveness of any medications you are taking.
- d. More information about T-cell and viral load tests can be found in Chapter 7 of your book.

3. **Say in your own words:** There are other tests, procedures and vaccinations that your health care provider may recommend. Some tests look to see if your medications are still working, some look at the state of your kidneys and liver, others measure your sugar or fat levels, and so on.
4. **Say in your own words, pointing to “Monitoring” on Chart 2:** Remember, “Monitoring” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



5. **Say in your own words:** Now we’ll move on to another important self-management tool in our Tool Box, Action-Planning.

Activity 5

INTRODUCTION TO ACTION PLANS

40 minutes

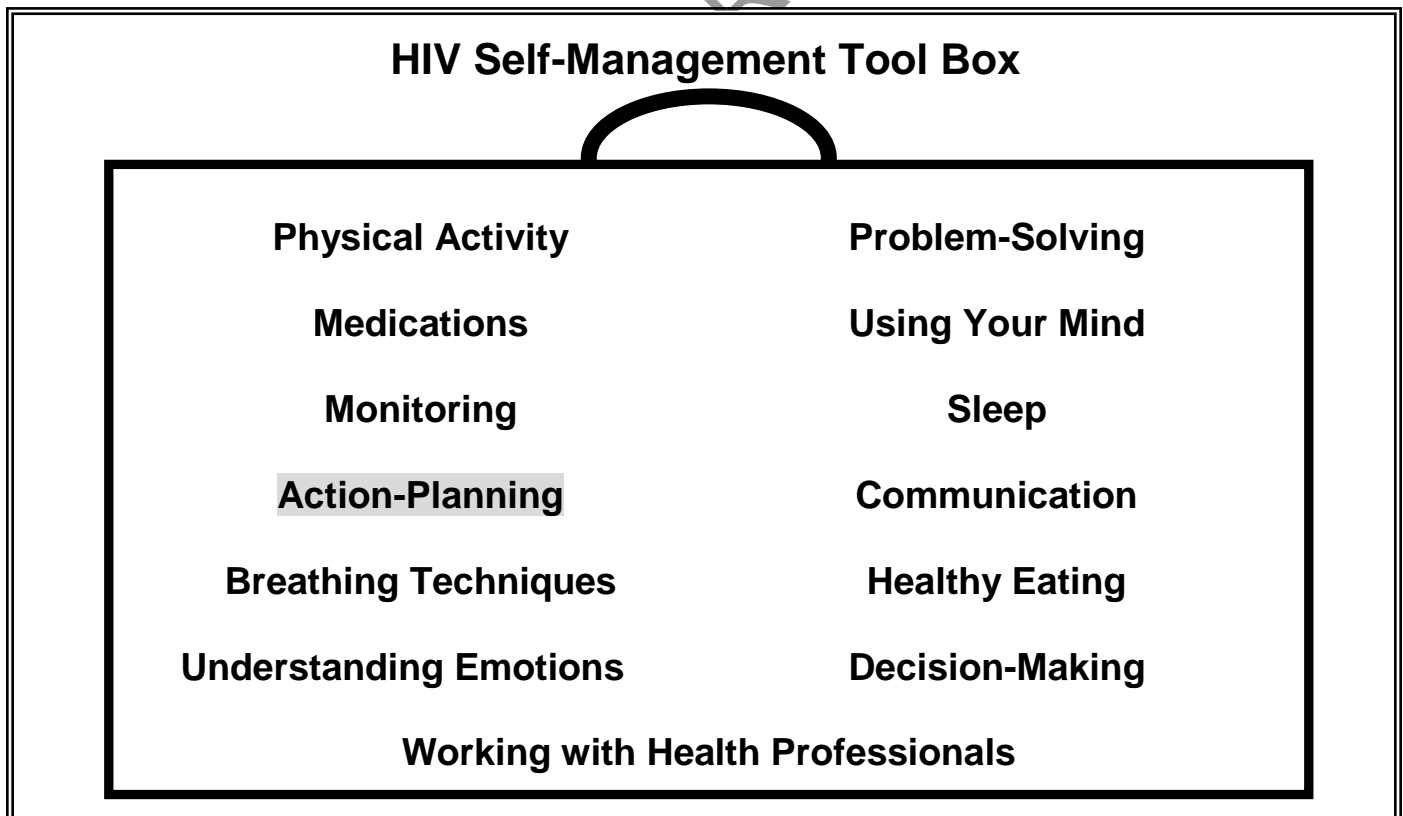
Materials

- Chart 2, “HIV Self-Management Tool Box”
- Chart 6, “Parts of an Action Plan”
- Action Plan Flow Chart, see Appendix II

1. **Say in your own words, using Chart 2, pointing to “Action-Planning” as you mention it:** Sometimes it can be overwhelming to think about the changes we want to make or the activities we want to accomplish. They seem too big to work on all at once, which makes it hard to get started.

To help with this, we have one of the most important self-management tools in our Tool Box - **action planning**. Action plans allow us to achieve what we want or decide to do by breaking down the activity into smaller, more “doable” steps or tasks.

Chart 2



2. **Say in your own words:** For example, a person who decides to find out about treatment options might break this goal into one of these steps as their first weekly action plan:
- One action plan might be to do research through your health care provider, local HIV organizations, friends who have found good resources for information, or reliable HIV internet sites
 - Another plan might be to make a list of questions to ask your healthcare provider
 - Another could be to ask your health care provider about therapies that he/she feels are most promising for you given your particular health issues and circumstances
 - And another could be to discuss your thoughts with someone close to you.
3. **Say in your own words:** We do not need to do all the steps at once. Rather, we need to get started by deciding which step we are going to work on **this week** and exactly how we are going to do it.
4. **Say, pointing at Chart 6:** This is done by making a **weekly action plan**. Here are the necessary parts of a successful weekly action plan:

(Chart 6 on the next page)

Parts of an Action Plan

1. **Something YOU want or decide to do** (*not what someone else thinks you should do, or that you think you should do*)
2. **Achievable** (*something you can expect to be able to do this week*)
3. **Action-specific** (*for example, gaining or losing weight is not an action or behavior, but adding or avoiding snacks between meals is; gaining or losing weight is the RESULT of actions*)
4. **Answer the questions:**
 - What? (specific action)** (*for example, walking or replacing junk food snacks with fruit*)
 - How much? (time, distance, amount)** (*for example, 30 minutes, or 4 streets, or 1portion.*)
 - When? (time of day or which days of the week)** (*for example, after dinner or Monday, Wednesday, Friday*)
 - How often? (number of times in the week)** (*for example, 3 times; avoid "every day", if something comes up, it's better to have succeeded when you say you'll do something 3 times rather than to feel you've failed if you've done it 6 times; you feel even better if you do it 7 times when you've said you'll do it 3 or 5 times!*)
5. **Confidence level of 7 or more** (*Ask yourself, "On a scale of 0=not at all sure to 10=totally sure, how sure am I that I will complete the ENTIRE action plan?" If you rate your confidence below a 7, you might want to look at the barriers and consider reworking your action plan so that it's something you are confident that you can accomplish. It's important that you succeed!*)

5. **Say in your own words:** We will give more examples by telling you our action plans for the week and then discuss how to make an action plan. I'll start.

6. **Instructions to Leaders:** One leader should go through each step on Chart 6 (pointing at each step while standing next to it), using their own action plan. Start by saying what you are trying to accomplish such as exercise more.

IMPORTANT
MODELING
MOMENT



PREPARE BEFORE SESSION: Leaders should prepare action plans in advance with each other, remembering that the leaders' action plans will be

MODELS for the rest of the participants. This means that your action plan should be something you really want to do and will complete.

If possible, at least one leader's action plan should be around behaviors taught in the workshop (e.g., exercise or relaxation techniques). Also, it should appear reasonable to the participants. (For example, even if you walk 5 miles a day, tailor your action plan so it is not too intimidating to the group. Make a plan for a half a mile a day instead.)

Leaders should make action plans around different things, for example, one might be about exercise, and the other about relaxation. Be careful to make the action plan for 3-4 times a week, rather than 5-7, and report a confidence level of 7-9.

7. **Say in your own words:** Now my partner will share their plan.

IMPORTANT
MODELING
MOMENT



Instructions to Leaders: The second leader reports their action plan, answering each of the questions on Chart 6 as the first leader points to them.

8. **Instructions to Leaders:** Emphasize that action plans must be:

- something you **want or decide to do**
- **achievable**, that is you can expect to achieve it in the next week

9. **Say in your own words:** Now you are going to help each other make action plans for this week.

- We want you to break into pairs. **You should not pair with someone you came with.**
- Each person in the pair helps the other person to make an action plan.
- After 10 minutes we'll get back together, and you will report your action plan back to the entire group. We will let you know when about half the time is up, so you can switch, and both have an opportunity to make a plan.
- Remember, the action plan can be for **anything** you want or decide to do.

10. **Instructions to Leaders:** After 4 minutes, remind the group that they should switch.

After 9 minutes, tell the group that they have 1 minute left.

11. **Instructions to Leaders:** Reconvene the group. Suggest that participants write down their action plans if they wish (remember that not everyone can write so this should not be a direction but a suggestion).

An example of an action plan form can be found on page 31 of their book, *Living a Healthy Live with HIV*, or participants may wish to hand copy the format for use in the workshop from the chart, but **do NOT offer to copy a form for them!** (This is a self-management workshop.) If you think that some members of your group don't read, you may leave this out.

12. **Say in your own words:** Please tell us your action plan for this week, and how sure you are that you will complete the plan, 0 being not at all sure and 10 being totally sure.

This number is **not** the percentage of the action plan you believe you can complete, but how sure you are that you can complete the **whole** action plan.

13. **Instructions to Leaders:** Ask for a volunteer to start reporting actions plans and then go around the room from that person (do not ask for a second volunteer).

Point to each step (what, how much, when, how often, confidence level) on Chart 6 as each participant reports their plan.

See Appendix II, Making an Action Plan Flow Chart. While one Leader is talking with the group, the other Leader is following the flow chart and can comment if something is missed that the co-leader conducting the exercise did not catch.

14. **Instructions to Leaders:** If confidence level is less than 7, ask the participant what the problem might be and if they encounter the problem, what would they do.



Ask the participant if they would like suggestions from the group.

If the participant says “yes”, have the group offer suggestions and ask the original participant to listen carefully without comment. You do not need to write on the board or chart pad.

After all the comments, ask the participant: “if you have (name the problem) what will you do?” Participants can change their plan at that moment if they wish.

Ask the participant to state the new or amended action plan, starting with “I will.” You may repeat this process with other participants if necessary.

15. **Instructions to Leaders:** If someone is having trouble writing a clear action plan (i.e. specific activity, times per day, days per week), go through the same steps as above, **asking other group members for suggestions** *before* you help.

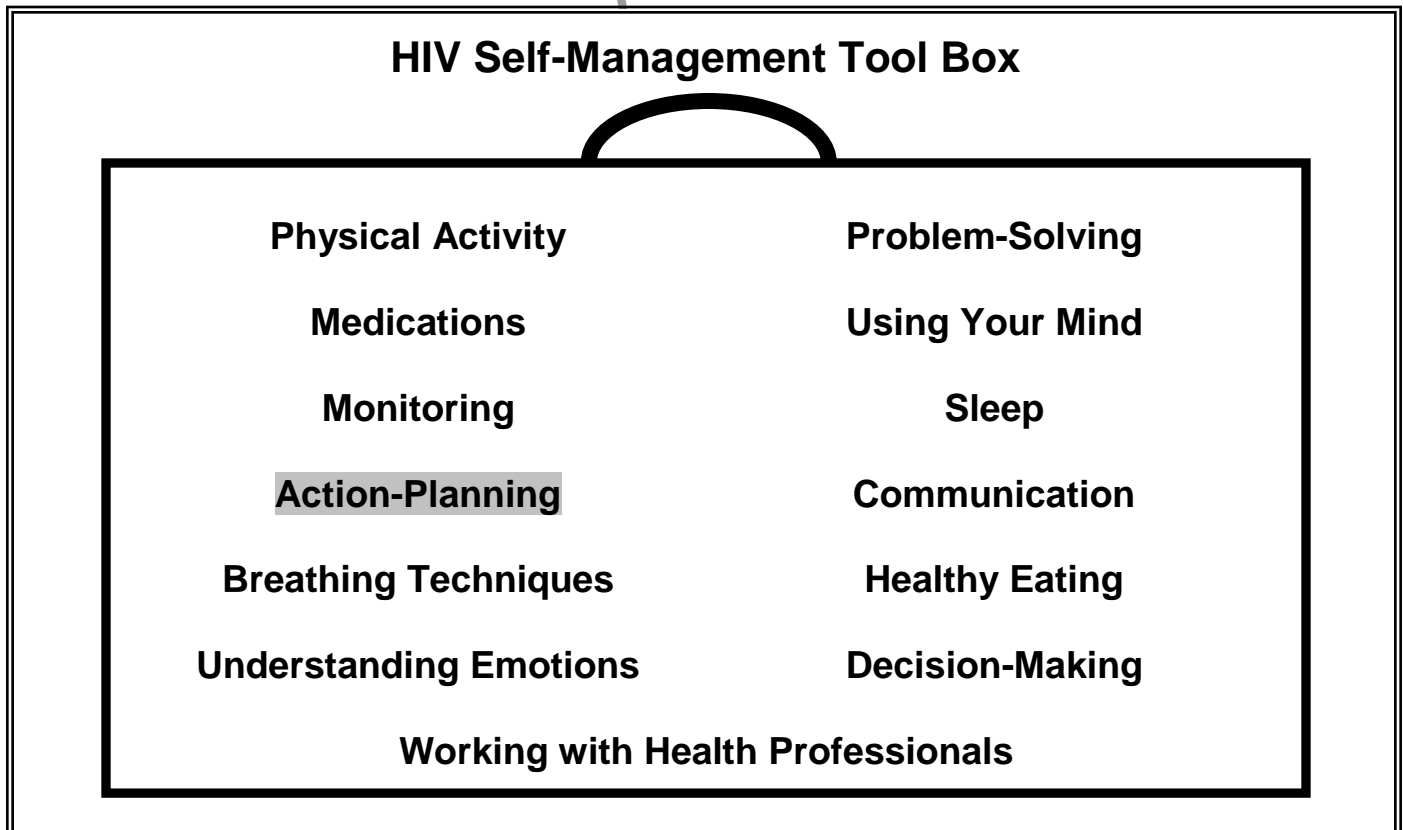
Do not spend more than 3 minutes with any one person. If someone is having problems, work with them individually *afterwards*.

If someone does not want to make an action plan say that is OK and that you will come back to them later—then go back to the person after everyone has made their plan. If they still do not want to make a plan that is OK.

16. **Instructions to Leaders:** Inform the participants that the leaders will be calling them once during the coming week to support them in their action plans.

17. **Say in your own words, pointing to “Action-Planning” on Chart 2:** Remember, “Action-Planning” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



Activity 6

CLOSING

10 minutes

1. **Instructions to Leaders:** Invite participants to review what was covered today in the book, *Living a Healthy Life with HIV*. Let them know that the book is not a workbook, but a reference book, so there is more in the book than is covered in the workshop.

The reading for each session is listed on the back of their “Workshop Overview” handout.

2. **Say in your own words:** Next week we will be talking about **making decisions**. Please think of something in your life for which you need to make a decision and have it ready for next week’s activity. We will also be covering **managing fatigue, difficult emotions, and problem-solving**.

3. **Instructions to Leaders:** Remind participants to **keep track of their action plans** daily and to be ready to tell the group about them next week.

4. **Instructions to Leaders:** Suggest to participants that they practice distraction a few times during the week.

5. **Instructions to Leaders:** Thank everyone for coming. Depending on your organization, remind them that one of the leaders will be contacting them (either by phone or email) during the week to see how things are going.

6. **Instructions to Leaders:** Collect name tags.

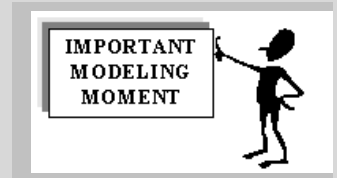
7. **Instructions to Leaders:** Stay around for 15 minutes or so to answer questions and straighten the room.

(See Note to Leaders on the next page)

SPECIAL NOTE TO LEADERS

- Leaders have the strongly suggested option to contact participants between Session 1 and Session 2 to support them in their action plan.
- Leaders should split up the class list, each leader calling or emailing half of the participants. If no one answers, and there is voicemail, be sure to leave a message for the person.
- When you call, **MODEL** how participants will be calling each other in later sessions.
- **BE BRIEF:**

“Hi, this is Chris from the Positive Self-Management Workshop. How are you doing with your action plan?” “Mine is to cook three healthful meals this week. I’ve done it twice so far, so things are going well. I’m looking forward to hearing about your success next week.”



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Purpose

- To report on action plans from last week
- To introduce problem-solving techniques
- To introduce the causes of fatigue
- To discuss strategies for reducing fatigue
- To introduce and practice decision-making strategies
- To discuss difficult emotions and ways to manage them

Objectives

By the end of the session, group members will be able to:

1. Name the steps of problem-solving
2. Describe at least 1 new method of dealing with fatigue
3. Identify the steps of decision-making
4. Practice decision-making skills
5. Share with and help another person discuss causes of difficult emotions
6. Name at least 2 ways to manage difficult emotions
7. Make an action plan for the coming week

Materials

- Charts:
 - 2: HIV Self-Management Tool Box (**post at all sessions**)
 - 3: Guidelines (**post at all sessions**)
 - 4: Brainstorming (**post at all sessions**)
 - 6: Parts of an Action Plan (**post at all sessions**)
 - 7: Problem-Solving Steps (**post at all sessions**)
 - 8: Symptom Cycle (**post at all sessions**)
 - 9: Decision-Making Steps
 - 10: Example of Decision to Be Made
- Name tags
- Easel, flip chart/felt pens or blackboard and chalk
- *Living a Healthy Live with HIV*
- Pad of paper, extra pencils
- Kleenex

Homework Assignments Given During Session 2

- You may want to keep a journal of their feelings.
- During the week carry out your action plan and note if there are any challenges and how you overcame them.
- Call your buddy to support each other in your action plans (optional)
- Reading: *Living a Healthy Life with HIV*, pages 20-24, 138-140, 152-164

Reading for Leaders' Preparation

- *Living a Healthy Life*: as homework assignment, above
- Making an Action Plan Flow Chart, Appendix II
- Feedback Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of the session:

Session Two Agenda

Activity 1: Feedback/Problem-Solving (30 minutes)

Activity 2: Managing Fatigue (15 minutes)

Activity 3: Making Decisions (20 minutes)

BREAK (20 minutes)

Activity 4: Dealing with Difficult Emotions (40 minutes)

Activity 5: Making an Action Plan (20 minutes)

Activity 6: Closing (5 minutes)

Activity 1

FEEDBACK AND PROBLEM-SOLVING

30 minutes

Materials

- Chart 7, "Problem-Solving Steps"
- Feedback Flow Chart, Appendix II

Instructions to Leaders: Encourage participation of all members. Not more than 3-5 minutes should ever be spent on one person. People who discuss their action plans earlier will probably need more time than those who come later. Do not spend all of your time with "yes buts" or other "real" problem people (the general rule is that if someone has said "yes but" three times, you should go on to someone else. Deal with these folks during the break. Please review the **Feedback Flow Chart in Appendix II** to help you make appropriate responses to each participant. This activity works best if one Leader leads the activity and the second Leader follows the feedback with the flow chart and helps as needed.

1. **Say in your own words:** Welcome back! First, we are now going to report back on the action plans we made last week. Each of us will share our experiences in completing our action plans.

I'll start, and then my partner will report.

IMPORTANT
MODELING
MOMENT



Instruction to Leaders:

- Start with yourself as a model but make it very short.
- Be sure at least one Leader models a plan that has been accomplished, and if the other Leader had to modify that the modification process is modeled and that they were successful.

2. **Say in your own words:** Now we'd like to hear about your action plans. We'll start with the first volunteer and will go around the room from that person.
 - a. First, tell us what your action plan was for the past week.
 - b. Then tell us how well the action plan was accomplished. You can use words like:

- accomplished
- partially accomplished
- was not able to accomplish
- changed it to another plan

Sometimes plans need to be changed and if this occurred and you substituted something else, this is good self-management.

- c. Finally, if you were not able to accomplish your plan or if you changed your plan, describe the barriers that prevented you from completing your action plan or caused you to change it. If you changed it, tell us how you changed it.

3. Instructions to Leaders: Respond to each participant as follows

In addition to the following instructions, make sure you review the Feedback Flow Chart in Appendix II

If someone reports their confidence level ↓	If they were successful ↓	If they met obstacles and adjusted or changed their action plan successfully ↓	If there were problems and the person was partially successful ↓	If there were problems and the person was unsuccessful ↓
tell them that we don't need to report confidence levels from last week	congratulate them	congratulate them for being a good self-manager	comment on the good start they have made (but do not congratulate), and then problem-solve (see problem-solving steps below) with the group, if the person wishes to do so	go through the steps of problem-solving:

Problem-solving Steps with the group:



STEP 1

Ask the person to state the problem they had in completing the plan. Ask them to be specific.

STEP 2

Ask the person if they have any ideas of how to solve the problem or did they try a solution. Stop here if the person has ideas or has already tried a solution.

STEP 3

If the problem is not solved, ask the individual if they would like to hear some suggestions from the group on how to solve the problem. If yes, then continue with the brainstorm in the next steps. If not, move on to the next participant.

STEP 4

Ask the group **to give 4 or 5 possible solutions**. These suggestions should be given without comment or discussion.

STEP 5

Tell the person with the problem that they just listen and get ideas. The group leaders can also offer suggestions, but *not until* others in the group have participated.

STEP 6

When you have possible solutions (not more than 5 or 6), stop the suggestions or if you see there are more ideas, tell the group that you'll take one more and then stop. Suggest that they catch the person at break.

Leaders may write these on the board or flip chart or suggest that the person with the problem also writes these down. If you suspect that your group may have people who cannot read, suggest that they remember the ideas instead of writing them down. They do not have to write the suggestions unless they want to do so.

STEP 7

Ask the original participant if they could use any of the strategies suggested and, if so, which one. Recommend that the participant make a note of the helpful suggestion or remember it.

If no suggestions seem workable, then say you will talk with the person more during the break - and do so.

REMEMBER, DO NOT SPEND A LOT OF TIME ON ANY ONE PERSON. If a participant gives excuses why something won't work, go on to the next person after three "Yes buts."

4. **Say in your own words, if you were able to do a problem-solve during the feedback:** Throughout the workshop, we will be solving problems in the same way we just did. Problem-solving is another of the important tools in self-management and in life, so let's take a look at the steps we can use to solve problems.

Say in your own words, if there were no problems during feedback:

Throughout the workshop, we will be solving problems that might come up. Problem-solving is one of the most important tools in self-management and in life, so let's take a look at the steps we can use to solve problems.

5. **Instructions to Leaders: Refer back** to one of the problems just discussed, or if no one had a problem, **use an example of your own** as you **point at the steps on Chart 7:**

(Chart 7 on next page)

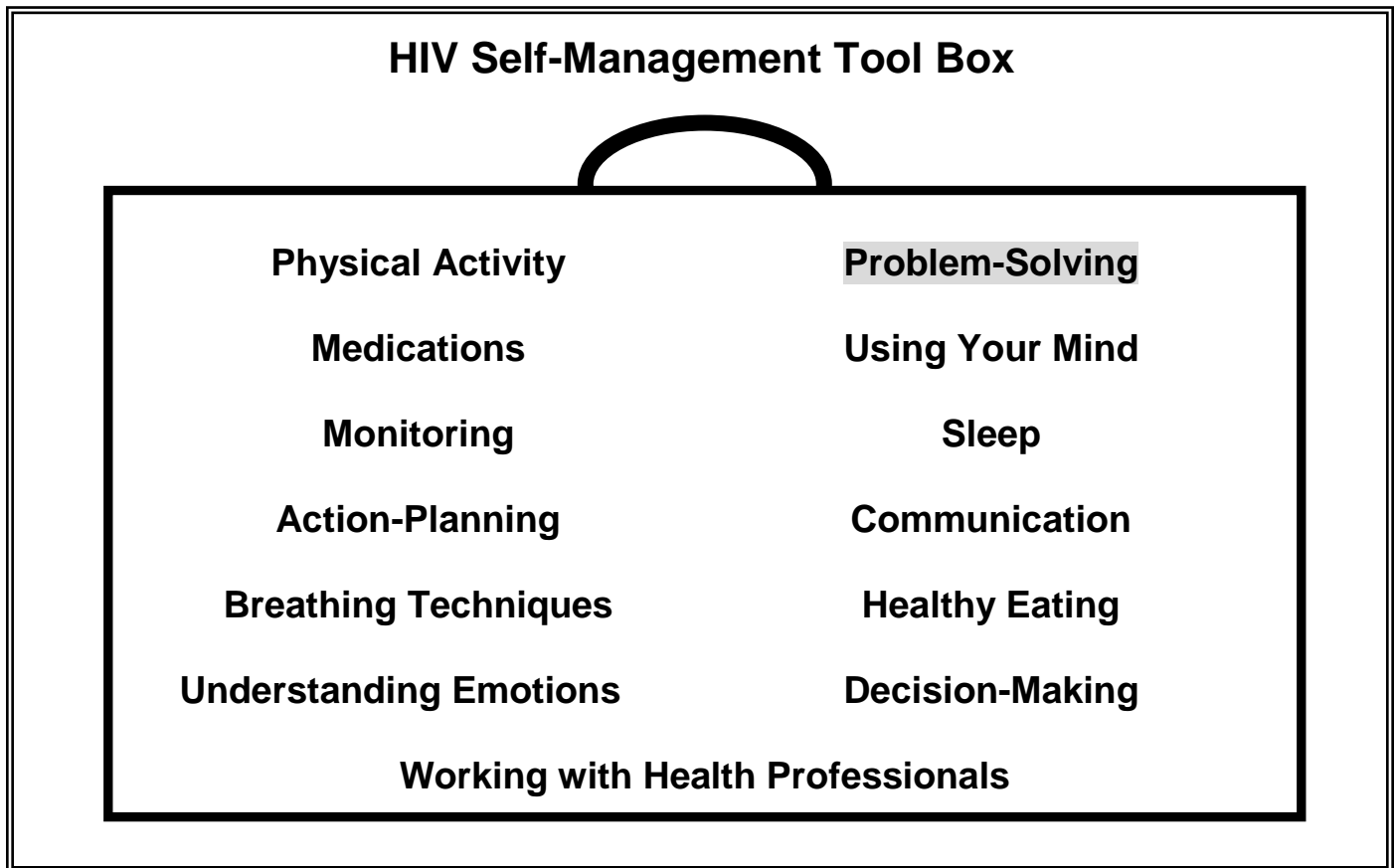
Problem-Solving Steps

1. **Identify the problem** (*this is the most difficult and most important step. For example, forgetting to take medications may be the stated problem, but the real problem may be avoidance due to unpleasant side effects.*)
2. **List ideas** to solve the problem. (*examples of ideas might be:*)
 - (*keeping a medication log to track side effects*)
 - (*calling the doctor to discuss side effects or alternative medications*)
 - (*adjusting time of taking medication slightly to a time when they don't interfere as much with other activities*)
3. **Select one** method to try. (*For example, keeping a medication log may reveal a pattern of times or days when the side effects are more severe, which can be presented to the doctor to discuss alternatives.*)
4. **Check the results** (*if the problem is solved – great! If not...*)
5. **Pick another idea** (*from the list if the first didn't work, or one of your own. Continue assessing the results and substituting ideas until you've used all the ideas on your list. If the problem still isn't solved...*)
6. **Utilize other resources** (*to make another list. Ask friends, family, or professionals for ideas if your solutions didn't work, then go back to Step 3, and continue until you've used all the items on your new list. If your problem is still not solved, then...*)
7. **Accept that the problem may not be solvable now** (*but it can be revisited at another time*)

6. **Say in your own words:** Now let's move on to discuss one of the common symptoms we have to deal with, fatigue.

7. **Say in your own words, pointing to "Problem-Solving" on Chart 2:** Remember, "Problem-Solving" is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



Activity 2 MANAGING FATIGUE

15 minutes

Materials

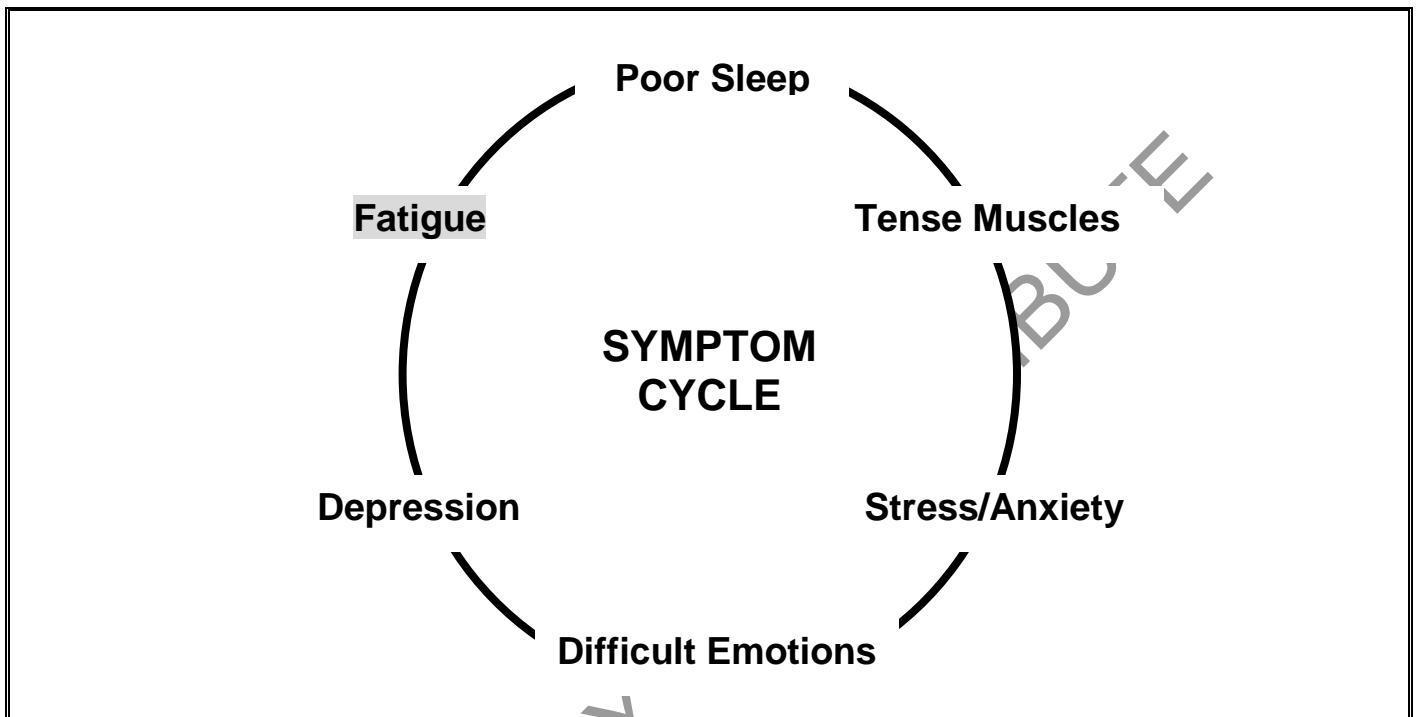
- Chart 8, "Symptom Cycle"

1. **Say in your own words, using Chart 8, remembering to point to each word on the cycle as you mention it:**

Many people assume that the symptoms they are experiencing are due only to the disease or its treatment. While the health condition can certainly cause poor sleep, stress, fatigue, and so on, it is not the only cause. Each of these symptoms can by themselves contribute to the other symptoms, and all can make each worse.

Even worse, these symptoms can feed on each other. For example, depression causes fatigue, stress and anxiety can lead to poor sleep, and these can lead to more tense muscles, and so on. The interactions of these symptoms, in turn, make our disease/condition worse. It becomes a **vicious cycle** that only gets worse unless we find a way to break the cycle.

Chart 8



2. **Say in your own words:** By understanding this Symptom Cycle and how each symptom contributes to the others, we can learn to use the different tools in our Tool Box to help break the cycle at these various points.
3. **Say in your own words, pointing to “Fatigue” on Chart 8:** One common symptom shared by people living with HIV is fatigue. Many people think that the fatigue is caused by HIV itself, but it can also have many other causes.

(Brainstorming Guidelines for Leaders on the next page)

Brainstorming Guidelines for Leaders

- The facilitator reads the question as written in the manual.
- The scribe writes the brainstorm question, using KEY words.
- The facilitator repeats the ideas loudly, using the participant's own KEY words while looking at group, not at the scribe.
- If the idea is too long, ask the participant to shorten it. If they cannot, ask for permission from them if you shorten or rephrase it.
- The scribe listens only to the co-Leader and writes what the facilitator says.
- The scribe does not use abbreviations or symbols.
- The scribe is responsible for telling the facilitator if they can't keep up with the ideas.
- The facilitator controls the "traffic"- slowing the brainstorm if the scribe needs to catch up.
- Neither the facilitator nor the scribe comment or allow anyone else to comment on the ideas (positively or negatively, verbally or by facial expression).
- The facilitator does not allow questions until after the brainstorm is over.
- If there are fewer than 15 ideas, the facilitator uses silence **...W...A...I...T...!** (it's not over until you have counted to 15 to yourself with no new ideas). If there are no more, the brainstorm is over.
- The facilitator does NOT call on people.
- The scribe tells the facilitator when there are 15 ideas listed.
- If there are 15 ideas, the facilitator tells the group you will take 2 more and end the brainstorm.
- After the brainstorm, the scribe or facilitator reads back the list to the group.
- The facilitator asks if any ideas need clarification.
- If there are ideas listed in the manual to add, the facilitator adds only those ideas that are not already listed.
- If any ideas are "inappropriate", such as alcohol or violence, the facilitator points this out politely without pointing anyone out.

4. **Say:** Let's do a brainstorm. The question is:



What are some of the causes of fatigue?

Instructions to Leaders: After the brainstorm, read over the list, ask if any need clarification, and then add any of the following, **if they are not mentioned:**

- a. Condition itself - such as pain from inflammation, joint or tissue damage, poor blood supply to the heart, trapped or damaged nerves, and fatigue because the body is less efficient and takes more energy to heal itself.
 - b. Inactivity - causes de-conditioning; the body is less efficient.
 - c. Stress, anxiety or other difficult emotions.
 - d. Poor nutrition - poor quality, or not enough quantity
 - e. Insufficient rest - not enough sleep or poor-quality sleep. Many people who wake up tired after a full night's sleep may have a sleep disorder and do not know it
 - f. Muscle tension
 - g. Depression - fatigue is a major symptom of depression.
 - h. Medication side effects - fatigue can be one of the physical side effects.
 - i. Dehydration or not having enough water and fluids in your body - This is particularly important for you if you're taking some blood pressure medications or diuretics – water pills. You should avoid dehydration with these because it is hard on your kidneys. Taking in fluids does not worsen fluid retention unless your kidneys are impaired, and your doctor has you on fluid restrictions.
5. **Say in your own words:** Just as there are many causes of fatigue there can also be many ways to help manage it.

6. **Say:** Let's brainstorm again. The question this time is:



What are some things we can do to manage fatigue?

Instructions to Leaders: After the brainstorm, read over the list, clarify any if needed, and add any of the following if not mentioned:

- a. Not overdoing it
- b. Planning the day, so as to mix rest with activity
- c. Relaxation and other activities using the mind

- d. Resting or getting good sleep
 - e. Exercising
 - f. Remaining socially active
 - g. Learning to say NO
 - h. Eating a well-balanced diet, including plenty of fluids
 - i. Discussion with your healthcare provider regarding proper use of medications, side effects, dosing, etc.
7. **Say in your own words:** Later on in the workshop we will be looking at other ways to manage fatigue such as exercise and healthy eating as well as learning how to plan activities and how to say “no” with better communication. You can also find much more information in your book. We’re going to discuss one tool that can be very helpful, decision-making, next.

Activity 3

MAKING DECISIONS

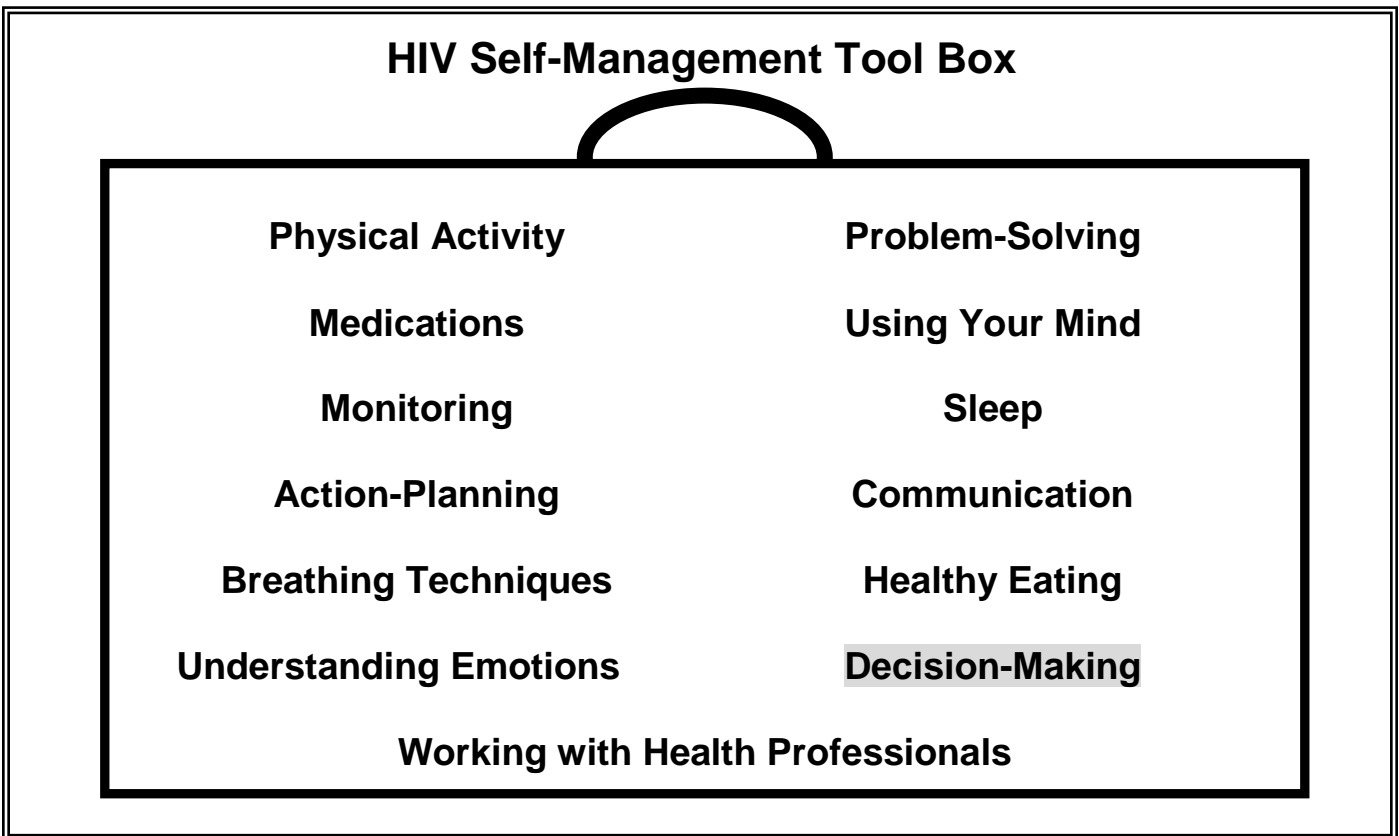
20 minutes

Materials

- Chart 2, “HIV Self-Management Tool Box”
 - Chart 9, “Decision-Making Steps”
 - Chart 10, “Example of Decision to be Made”
 - Blank paper and pencils
1. **Say in your own words, pointing to “Decision-Making” on Chart 2:** In life we are all faced with having to make decisions.

(Chart 2 on the next page)

Chart 2



2. **Say in your own words:** For people who are living with or affected by HIV, however, this can be challenging because we have to make these decisions during times of uncertainty.

Therefore, developing good decision-making skills is another self-management tool. Let's look at some steps to help us make decisions and then we'll see an example before we practice.

Instructions to Leaders: Display Charts 9 and 10 next to each other.

(Chart 9 on the next page)

Decision-Making Steps

1. **Identify the options** *(for example: someone trying to decide whether or not to join a support group or whether to take a trip)*
2. **Write down the “Pros” and “Cons” for each option** *(list as many reasons for and against each option as you can. Don’t forget emotional reasons, such as fear of being identified, or travelling away from your regular health care team)*
3. **Give a score to each statement from 1 being not important to 5 being very important**
4. **Add each column and compare the results to find the higher score**
5. **Ask yourself how this option meets the “gut test”** *(for example, Does joining a support group or going on the trip feel “right” to you? If so, you probably have a decision. If not, the gut test should probably win out over the math. It is a good idea to remember, though, that for people struggling with alcohol or other addiction, that you don’t confuse your gut with your addiction talking to you.)*

3. **Say in your own words:** Here’s an example of how any decision could be made using these decision-making steps.

Instructions to Leaders: Point also to the Decision-Making Steps on Chart 9 as you describe this example on Chart 10.

4. **Say in your own words:** Suppose that your health care provider has suggested that you should join a support group and you want to decide if this is something you want to do:
- The first thing to do is to list all the reasons for joining a support group - the “Pros”. These are things that you think might be good if you joined a support group. In our example, “it might make me feel better”, “I might meet new people like me”, and so on.
 - Then do the same for reasons against joining a support group – the “Cons”. These are things that you might think are bad such as “There might be people I know”, “It could be depressing and focus on negative things”, and so on.

- Once you have all the “Pros” and “Cons” listed, score each of them by **how important** they are to you on a scale of 1-5, 1 means it’s not important, and 5 means very important.
 - After you have scored each of the reasons, add up the scores in each column. As you can see, the total for all the “Pros” was 14 and the “Cons” total was 11.
 - The higher score shows your decision: Join a support group.
 - However, and this is important, you then do the “gut test”. You ask yourself: “Does my gut - or intuition - tell me that I should join a support group?”
 - If your answer is “yes”, you have your decision. **But** if your gut tells you “no”, go with your gut and your decision is “no”. You may consider exploring this further with someone else. In this example, discuss your decision with your health care provider or support person.
5. **Say in your own words:** Even if your gut tells you “no”, this decision-making technique helps you with that decision, as it helps you understand the reasons for your decision.

(Chart 10 on the next page)

Example of Decision to be Made:

“Should I join a support group?”

<u>Pro</u>	<u>Score</u> <u>1 - 5)</u>	<u>Con</u>	<u>Score</u> <u>1 - 5)</u>
It might make me feel better	5	There may be people who I know	4
I will meet new people like me	4	It could be depressing and focus on negative things	1
It will help me learn about HIV and find out up to date information	5	Initially it's too hard to go as I'm scared	4
		The timing of the group may not work	2
<u>Pros Total</u>	<u>14</u>	<u>Cons Total</u>	<u>11</u>

The “Pros” total is greater than the “Cons”

Decision result is : To join a support group

Ask the question: “Does this meet the ‘gut test’?”

- Say in your own words:** Now let’s practice this for ourselves. We’re going to break into pairs and help each other with making a decision using this “pro and con” technique. The decision can be related to the day-to-day management of your HIV or anything else. Use the Decision-Making chart to guide your conversation with your partner.

We will have 10 minutes to work on this activity. At the end of 10 minutes we will reconvene, and 1 or 2 people can share what decision they were trying to make and what decision was reached.

Remember, if you don't want something shared with the whole group, either don't use that example, or ask your partner not to discuss this with the group.

7. Instruction to Leaders: Now ask participants to break into pairs (or one group of 3 if odd numbers present).

Offer blank paper for participants to use if they want it. If someone does not want to write (or they cannot), they can just talk about the “pros” and “cons”.

One leader should keep time, letting participants know at 5 minutes that half the time has been used, and to switch if they have not already.

8. Instructions to Leaders: At the end of 10 minutes, reconvene the group and ask for 1 or 2 people to share (they report back for themselves). You might wish to write these on a blank flipchart:



- 1) The decision they were trying to make,
- 2) What were 2-3 of the Pros and Cons,
- 3) What the Pro and Con totals were, and
- 3) If that was what their gut told them.

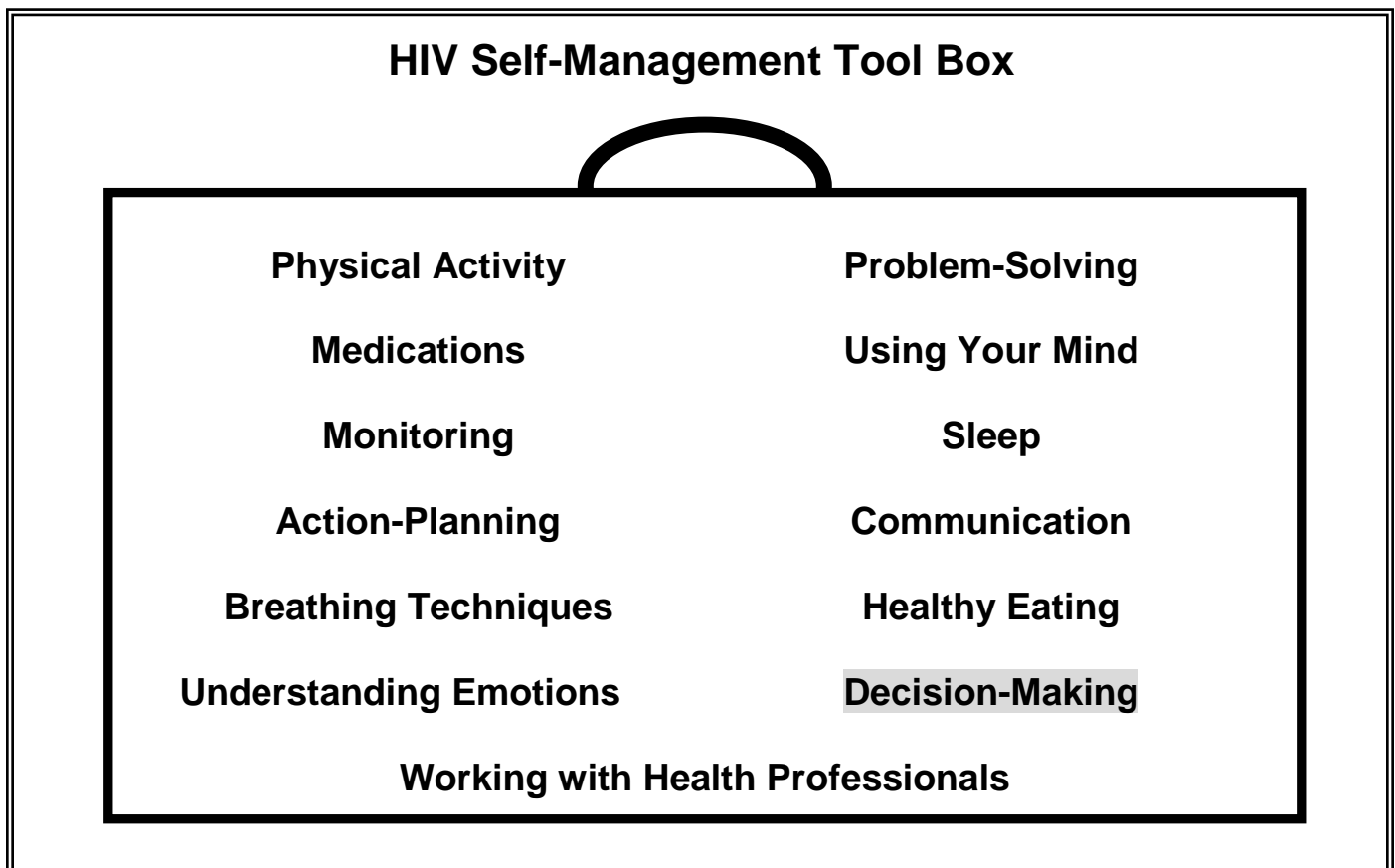
You will not have time for everyone to do this. If volunteers start sharing more details than requested, gently redirect them to answer just the 4 questions mentioned above.

9. Say in your own words: This decision-making technique is an important tool in our Self-Management Tool Box. If you still have decisions that you'd like to make, you may want to include it in your action plan for this week, which we will be making at the end of the session.

10. Say in your own words, pointing to “Decision-Making” on Chart 2: Remember, “Decision-Making” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



11. **Say in your own words:** Let's take a 20-minute break now. It's good to get up and move around.



BREAK

20 minutes

Activity 4

DEALING WITH DIFFICULT EMOTIONS

40 minutes

Materials

- Chart 8, “Symptom Cycle”
- Chart 4, “Brainstorming”

NOTE TO LEADERS

- The main purpose of this activity is to help people understand that the emotional ups and downs they experience living with or affected by HIV are normal, and to give people a chance to share and problem-solve on these issues.
- The problem-solving aspect is important, as it is part of what differentiates this activity from a standard support group in which the main purpose is to listen.
- People DO need to be listened to as well, which is why we ask that they pair up to share some of their experiences.
- The reason we then ask them to *share their partner’s experience* with the group rather than their own is to help each person know they have been heard; it also limits what is shared.

1. **Say in your own words, pointing to “Difficult Emotions” on Chart 8:** Today, we’re going to discuss how difficult emotions such as frustration, anger, fear, worry, or any other difficult emotion you may feel can feed the Symptom Cycle.

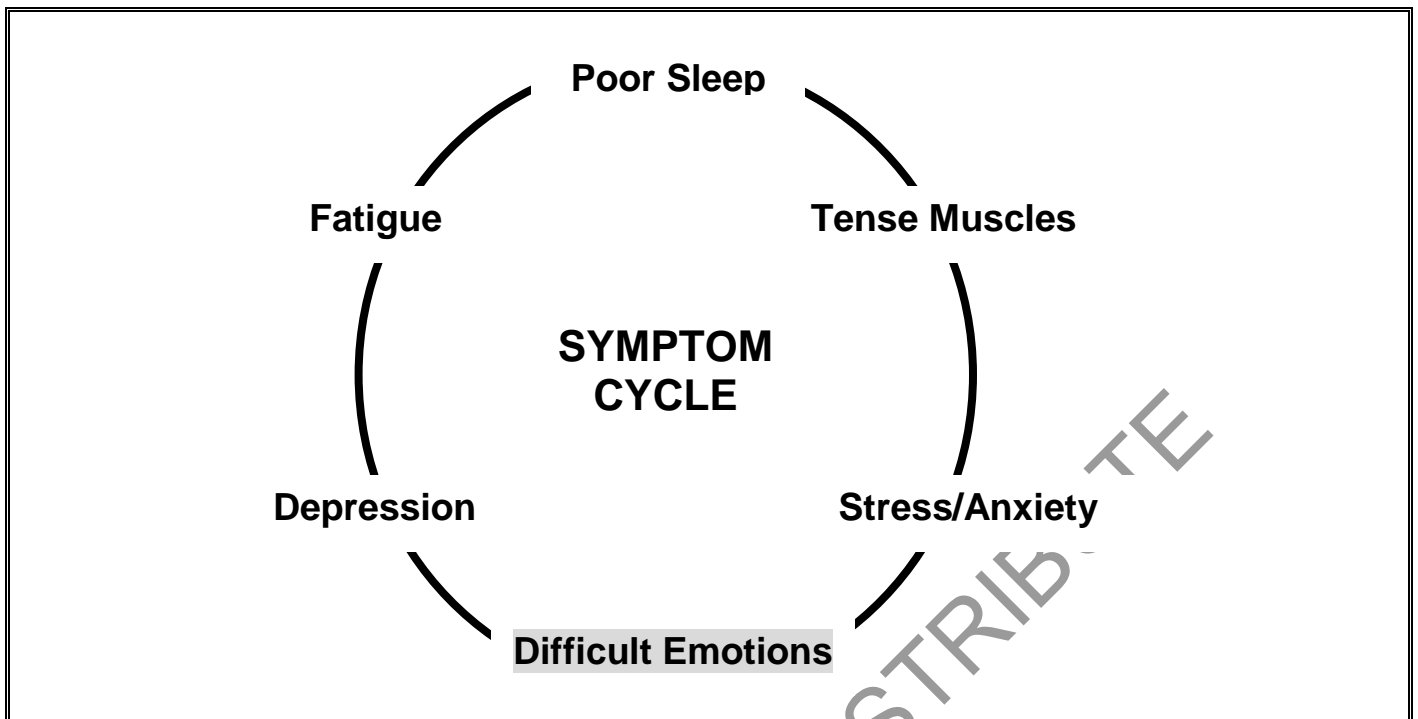
These feelings are common and normal for people with HIV or any other chronic or long-term physical or mental health conditions. They are other symptoms, just like fatigue, poor sleep, or stress.

When we are first diagnosed and even later, we can feel a loss of control over our lives. We worry about our future and about our relationships with other people, or feel angry with others, or ourselves, and about our status.

Again, these feelings are as normal as any other symptom, and happen to almost everyone.

(Chart 8 on the next page)

Chart 8



2. **Say in your own words:** How many people have felt angry, worried, depressed, frustrated, or any other difficult emotion about HIV or have fears about the future?



3. **Say in your own words:** In a minute, we will ask you to break into pairs to discuss the causes or reasons for your difficult emotions.

- a. Do not worry too much about what you call an emotion. Some people will talk about anger, others grief and others guilt. The name is not important, and we won't ask you to name the emotion.

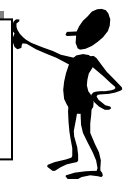
What is important is what **CAUSES** you to feel these difficult emotions? In other words, what is the reason for you to feel that way?

The **cause or the reason for your emotion** is what we'd like you to share.

For example, you may worry that your medication will stop being effective. The cause of your difficult emotions, then, is not knowing about the future.

4. **Instruction to Leaders: Model** examples of your own, making sure that you are modeling the **cause** of the emotion rather than the emotion.

**IMPORTANT
MODELING
MOMENT**



- a. Use an example of your own or use this example:

For me, what causes my difficult emotions is that my HIV status may become known at my job.

- b. The Co-Leader should write “Causes of Difficult Emotions” on the board or chart pad, and then the Leader’s own example that was just stated.
- c. Now the co-Leader shares their reason for difficult emotions and writes in on the board or chart pad.

5. **Say in your own words:** After you have paired up, you will have about 4 minutes, and then you will listen as your partner discusses the causes of their emotions. We will let you know when half of the time has passed, so you can make sure you have enough time for both of you to share.
 - a. After about 8 minutes, you will report to the group on what YOUR PARTNER shared. We want you to tell us what **caused** the emotions. We **don’t** want you to tell us things like “angry”, “guilty”, “sad”, or “scared”, but what made them feel that way.
 - b. **IMPORTANT:** If there is something you don’t want the whole group to hear, either don’t share it with your partner, or tell your partner not to share it with the group.

6. **Instructions to Leaders:** Tell the group to break into pairs. If you have a person without a partner and everyone else has partners, ask if anyone would take an extra person and allow a group of three. When everyone has a partner, begin timing.

- After 4 minutes, **remind the group** that they should switch.
- After 7 minutes, **tell the group** that they have 1 minute left.

NOTE

IMPORTANT NOTE TO LEADERS!
Do NOT allow the sharing in pairs to go longer than 10 MINUTES TOTAL!

7. **Instructions to Leaders:** After 8 minutes, **reconvene the group.**
8. **Say:** Briefly tell us what causes your sharing partner’s difficult emotions. You don’t need to name the emotions, just the causes.

Instructions to Leaders: Ask each person to report on the most important causes of these difficult emotions for his or her partner. Ask for a volunteer to start, and then ask their partner. From there, go around the room. Do not ask for a second volunteer.

The Leader not facilitating should write the **causes** of the emotions on the board or chart pad, taking care to **avoid** writing the name of the emotion.

- a. Ask people to be concise in their reports.
- b. At the end of each report, check with the partner to see that the report was correct, but don't allow the person to go into a lengthy "story." They should only correct any misinformation, not add new information. (Leaders need to be firm about this.)
- c. If a reason comes up more than once, make a check mark next to that reason.
- d. Read over the list generated.

9. **Say in your own words:** As you can see, there are many causes for difficult emotions. Now we're going to do a "**brainstorm.**" Remember that the purpose of brainstorming is to allow us to share as many ideas about a topic as possible in the quickest way possible. To do this, we'll be following these guidelines:

Instructions to Leaders: You do not need to go over the Brainstorming chart in detail, unless your group requires it.

Chart 4

Brainstorming

- **Anyone can share**
- **No commenting during brainstorm** (*about others' ideas, negative or positive*)
- **No questions until after** (*the brainstorm*)
- **Clarification waits until after** (*when all the ideas are out, we'll go over anything that needs clarification*)

10. **Say:** Here is the question we are going to brainstorm:

What are some ways to deal with difficult emotions?



11. **Instructions to Leaders:** Read over the list and ask if anyone needs clarification on any of them. Add any of the following *if they are not mentioned*.

- a. physical activity or exercise
- b. relaxation
- c. prayer or meditation
- d. call a friend or talk to someone
- e. get out or away from the house - socialize
- f. help someone else or do some volunteer work
- g. do something nice for yourself
- h. write your feelings down

12. **Instructions to Leaders:** Ask participants to volunteer any new things that they are going to use to deal with these emotions in the future. Just get a few examples; there is not enough time to have everyone give an example.



13. **Say in your own words:** Again, the emotions we've been discussing are just another symptom of our health problems – just like poor sleep and fatigue.

- a. You may want to continue exploring your feelings. One way you can do this at home is to write down your thoughts and feelings about different aspects of your lives, especially those you have never shared.
- b. You don't need to show this to anyone, and you don't even have to keep it.
- c. Psychologists have found that this practice of writing feelings down helps people feel and cope better with their problems.

14. **Say in your own words:** Another thing you can do is to take a few minutes each day to think about things for which you are grateful/thankful or things that make you happy, or made you smile that day.

We'd like you to think of one thing for which you are grateful/thankful and then

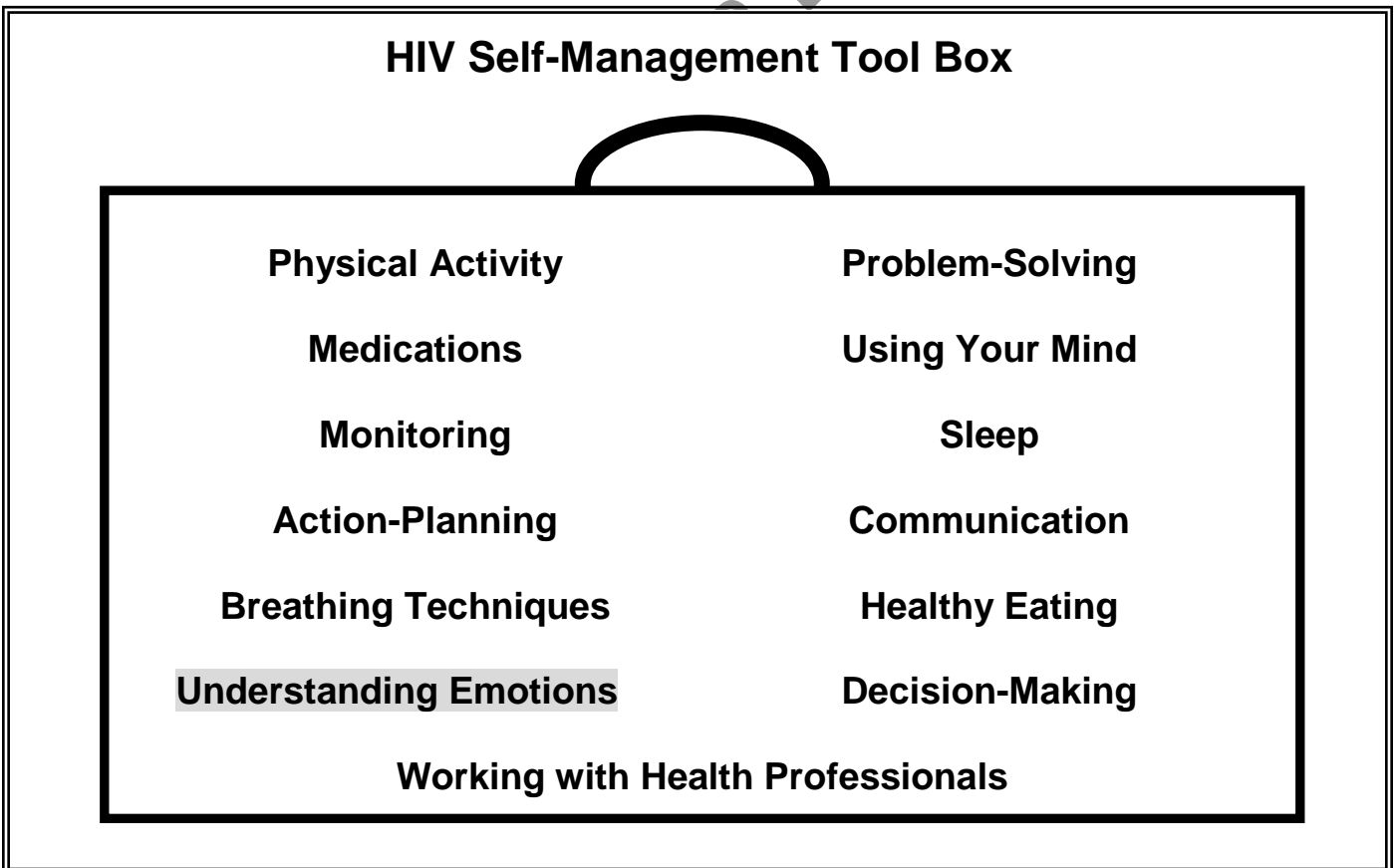
we'll go around the room and have each person tell us one thing for which they are grateful, or that has made them happy or smile today. We'll give you a moment to think about this before we share.

15. **Instructions to Leaders:** Give the group a minute or two to think, then start with yourself as a model and share your thoughts. Then ask for a volunteer and go around the room.

Leaders do not need to write these. If someone is having trouble thinking of something say that is OK and go on. Do not dwell on this.

16. **Say in your own words:** Some people keep a journal or diary where they write the things for which they are grateful or thankful, or made them happy. This can be a great action plan!
17. **Say in your own words, pointing to “Understanding Emotions” on Chart 2:** Remember, “Understanding Emotions” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



Activity 5

MAKING AN ACTION PLAN

20 minutes

Materials

- Chart 6, “Parts of an Action Plan”
- Action Plan Flow Chart, in Appendix II

1. **Say in your own words:** Now it’s time to make our action plans for this week. This is something we will do each week.

Remember that action plans allow us to achieve what we want or decide to do by breaking down the activity into smaller, more “doable” steps or tasks.

2. **Say:** Let’s briefly review the parts of an action plan:

Chart 6

Parts of an Action Plan

1. **Something YOU want or decide to do**
2. **Achievable** (*something you can expect to be able to do this week*)
3. **Action-specific** (*for example, gaining or losing weight is not an action or behavior, but adding or avoiding snacks-between meals is; gaining or losing weight is the RESULT of actions*)
4. **Answer the questions:**
 - What? (specific action)
 - How much? (time, distance, amount)
 - When? (time of day or which day of the week)
 - How often? (number of days in the week) (*avoid “every day”*)
5. **Confidence level of 7 or more** (*On a scale of 0=not at all sure to 10=totally sure*)

3. **Say in your own words:** We’ll start with our own action plans for the week.

IMPORTANT
MODELING
MOMENT



4. **Instructions to Leaders: One leader should go**

through each step on Chart 6 (pointing at each step while standing next to it), using his or her own action plan. Start by saying what you are trying to accomplish such as exercise more.

PREPARE BEFORE SESSION: Leaders should prepare action plans in advance with each other, remembering that the leaders' action plans will be **MODELS** for the rest of the participants. This means that your action plan should be something you really want to do and will complete.

If possible, at least one leader's action plan should be around behaviors taught in the workshop (e.g., exercise or relaxation techniques). Also, it should appear reasonable to the participants. (For example, even if you walk 5 miles a day, tailor your action plan so it is not too intimidating to the group. Make a plan for a half a mile a day instead.)

Leaders should make action plans around different things, for example, one might be about exercise, and the other about relaxation. Be careful to make the action plan for 3-4 times a week, rather than 5-7, and report a confidence level of 7-9.

5. **Say in your own words:** Now my partner will share their plan.

IMPORTANT
MODELING
MOMENT



Instructions to Leaders:

The second leader reports their action plan, answering each of the questions on Chart 6 as the first leader points to them.

6. **Instructions to Leaders:** Emphasize, pointing at Chart 6 that action plans must be:

- something you *want or decide to do*
- *achievable*, that is you can expect to achieve it in the next week

7. **Say in your own words:** Please tell us your action plan for this week, and how sure you are that you will complete the plan, 0 being not at all sure and 10 being totally sure.

8. **Instructions to Leaders:** Ask for a volunteer to start reporting action plans and then go around the room from that person (do not ask for a second volunteer).

Point to each step (what, how much, when, how often, confidence level) on Chart 6 as each participant reports their plan.

See Appendix II, Making an Action Plan Flow Chart

9. **Instructions to Leaders:** If confidence level is less than 7, ask the participant what the problem might be and if they encounter the problem, what would they do.



Ask the participant if they would like suggestions from the group.

If they say yes, have the group offer 4-5 suggestions and the original participant should not comment.

After all the comments ask the participant “if you have (name the problem) what will you do?” Participants can change the plan if they wish.

Ask the participant to state the new or amended action plan, starting with “I will”.

To help people make an action plan, refer to the Making an Action Plan Flow Chart in Appendix II.

10. **Instructions to Leaders:** If someone is having trouble writing a clear action plan (i.e. specific activity, times per day, days per week), go through the same steps as above, **asking other group members for suggestions** *before* you help.

Do not spend more than 3 minutes with any one person. If someone is having problems, work with them individually *afterwards*.

If someone does not want to make an action plan say that is OK and that you will come back to them later—then go back to the person after everyone has made their plan. If they still do not want to make a plan that is OK.

NOTE TO LEADERS: See Making an Action Plan Flow Chart in Appendix II for details on how to help someone make an action plan.

Activity 6

CLOSING

5 minutes

- 1. Instructions to Leaders:** Remind participants that they may want to keep a journal of their feelings.
- 2. Instructions to Leaders:** Remind participants about the review what was covered today in their book. Remind them that this is not a workbook, but a reference book, so there is more in the book than is covered in the workshop.

The reading for each session is listed on the back of their “Workshop Overview” handout.
- 3. Say in your own words:** Next week we will be discussing **HIV medications**, from starting to adhering to them, **informing our health care professionals** about our condition, more about **problem-solving** and a little about **relaxation**.
- 4. Instructions to Leaders:** Remind participants that they may wish to support each other’s progress and action planning during the week, so ask participants to choose a buddy (other than the person attending with them) to call or email this week. Explain that their calls should be short, just enough to give support to each other in sticking with their action plan. (Optional)
- 5. Instructions to Leaders:** Remind participants to **keep track of their action plans** daily and to be ready to tell the group about them next week.
- 6. Instructions to Leaders:** Collect name tags.
- 7. Instructions to Leaders:** Stay around for 15 minutes or so to answer questions and straighten the room.

Purpose

- To introduce participants to informing their healthcare team about their needs
- To assist participants in evaluating and monitoring symptoms
- To assist participants in learning how to maintain HIV medications
- To introduce some of the problems associated with taking HIV medications
- To assist participants to solve problems
- To introduce Relaxation Body Scan and breathing

Objectives

By the end of this session, group members will be able to:

1. State their role in reporting to their healthcare team
2. Evaluate symptoms using the F.A.S.T. check
3. Identify 2 support mechanisms for maintaining medication regimens
4. Start a medication/symptom log
5. Practice 2 breathing techniques
6. Practice Relaxation Body Scan
7. Make an action plan for the coming week

Materials

- Charts:
 - 2: HIV Self-Management Tool Box **(post at all sessions)**
 - 3: Guidelines **(post at all sessions)**
 - 4: Brainstorming **(post at all sessions)**
 - 6: Parts of an Action Plan **(post at all sessions)**
 - 7: Problem-Solving Steps **(post at all sessions)**
 - 8: Symptom Cycle **(post at all sessions)**
 - 11: Chris's Symptoms
 - 12: Take P.A.R.T.
 - 13: Do a F.A.S.T. Check
 - 14: Taking HIV Medications
- Name tags
- Easel, flip chart/felt pens or blackboard and chalk
- *Relaxation for Mind and Body: Pathways to Healing* CD (optional)
- CD player (optional)
- *Living a Healthy Life with HIV*
- Pad of paper, extra pencils
- Kleenex

Homework Assignments Given During Session 3

- Start a medication log and symptom diary
- During the week carry out your action plan and note if there are any challenges and how you overcame them.
- Call your buddy to support each other in your action plans (optional)
- Reading: *Living a Healthy Life*: Chapters 6, 8, 9, 10, pages 136, 142, 146-148, 172-176

Reading for Leaders' Preparation

- *Living a Healthy Life*: as homework assignment, above
- Making an Action Plan Flow Chart, Appendix II
- Feedback Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of session:

Session Three Agenda

Activity 1: Feedback (25 minutes)

Activity 2: Informing Your Healthcare Team (20 minutes)

Activity 3: Taking HIV Medication (20 minutes)

BREAK (20 minutes)

Activity 4: Problem-Solving (30 minutes)

Activity 5: Better Breathing and Relaxation Body Scan (15 minutes)

Activity 6: Making an Action Plan (15 minutes)

Activity 7: Closing (5 minutes)

Activity 1

FEEDBACK

25 minutes

Materials

- Feedback Flow Chart, Appendix II

Instructions to Leaders: Encourage participation of all members. Not more than 3-5 minutes should ever be spent on one person. People who discuss their action plans earlier will probably need more time than those who come later. Do not spend all of your time with "yes buts" or other "real" problem people (the general rule is that if someone has said "yes but" three times, you should go on to someone else. Deal with these folks during the break. Please review the **Feedback Flow Chart in Appendix II** to help you make appropriate responses to each participant. This activity works best if one Leader leads the activity and the second Leader follows the feedback with the flow chart and helps as needed.

1. **Say:** Welcome back! The first thing we're going to do today is to report back on the action plans we made last week. Each of us will share our experiences in completing our action plans.

I'll start, and then my partner will report.

IMPORTANT
MODELING
MOMENT



Instructions to Leaders:

- Start with yourself as a model but make it very short.
- Be sure at least one leader models a plan that has been accomplished.

2. **Say in your own words:** Now we'd like to hear about your action plans. We'll ask for a volunteer then go around the room from that person.
 - a. First, tell us what your action plan was for the past week.
 - b. Then tell us how well the action plan was accomplished. You can use words like:
 - accomplished
 - partially accomplished
 - was not able to accomplish

- changed it to another plan

Sometimes plans need to be changed and if this occurred and you substituted something else, this is good self-management.

- c. Finally, if you were not able to accomplish your plan or if you changed your plan, describe the barriers that prevented you from completing your action plan or caused you to change it. If you changed it, tell us how you changed it.

3. Instructions to Leaders: Respond to each participant as follows

In addition to the following instructions, make sure you review the Feedback Flow Chart in Appendix II

If someone reports their confidence level ↓	If they were successful ↓	If they met obstacles and adjusted or changed their action plan successfully ↓	If there were problems and the person was partially successful ↓	If there were problems and the person was unsuccessful ↓
tell them that we don't need to report confidence levels from last week	congratulate them	congratulate them for being a good self-manager	comment on the good start they have made (but do not congratulate), and then problem-solve (see problem-solving steps below) with the group, if the person wishes to do so	go through the steps of problem-solving:

Problem-solving Steps with the group:

STEP 1

Ask the person to state the problem they had in completing the plan. Ask them to be specific.



STEP 2

Ask the person if they have any ideas of how to solve the problem or did they try a solution. Stop here if the person has ideas or has already tried a solution.

STEP 3

If the problem is not solved, ask the individual if they would like to hear some suggestions from the group on how to solve the problem. If yes, then continue with the brainstorm in the next steps. If not, move on to the next participant.

STEP 4

Ask the group to **give 4 or 5 possible solutions**. These suggestions should be given without comment or discussion.

STEP 5

Tell the person with the problem that they just listen and get ideas. The group leaders can also offer suggestions, but *not until* others in the group have participated.

STEP 6

When you have possible solutions (no more than 5) stop the brainstorm, or if you see there are more ideas, tell the group that you'll take one more and then stop the brainstorm. Suggest that they catch the person at break.

Leaders may write these on flip chart or suggest that the person with the problem do so. If you suspect that your group may have people who cannot read, suggest that they remember the ideas instead of writing them down.

STEP 7

Ask original participant if they could use any of the strategies suggested and, if so, which one. Recommend that the participant make a note of the helpful suggestion or remember it.

If no suggestions seem workable, then say you will talk with the person more during the break - and do so.

REMEMBER, DO NOT SPEND A LOT OF TIME ON ANY ONE PERSON. AFTER THREE "YES BUTS," GO ON TO THE NEXT PERSON.

Activity 2

INFORMING YOUR HEALTHCARE TEAM

20 minutes

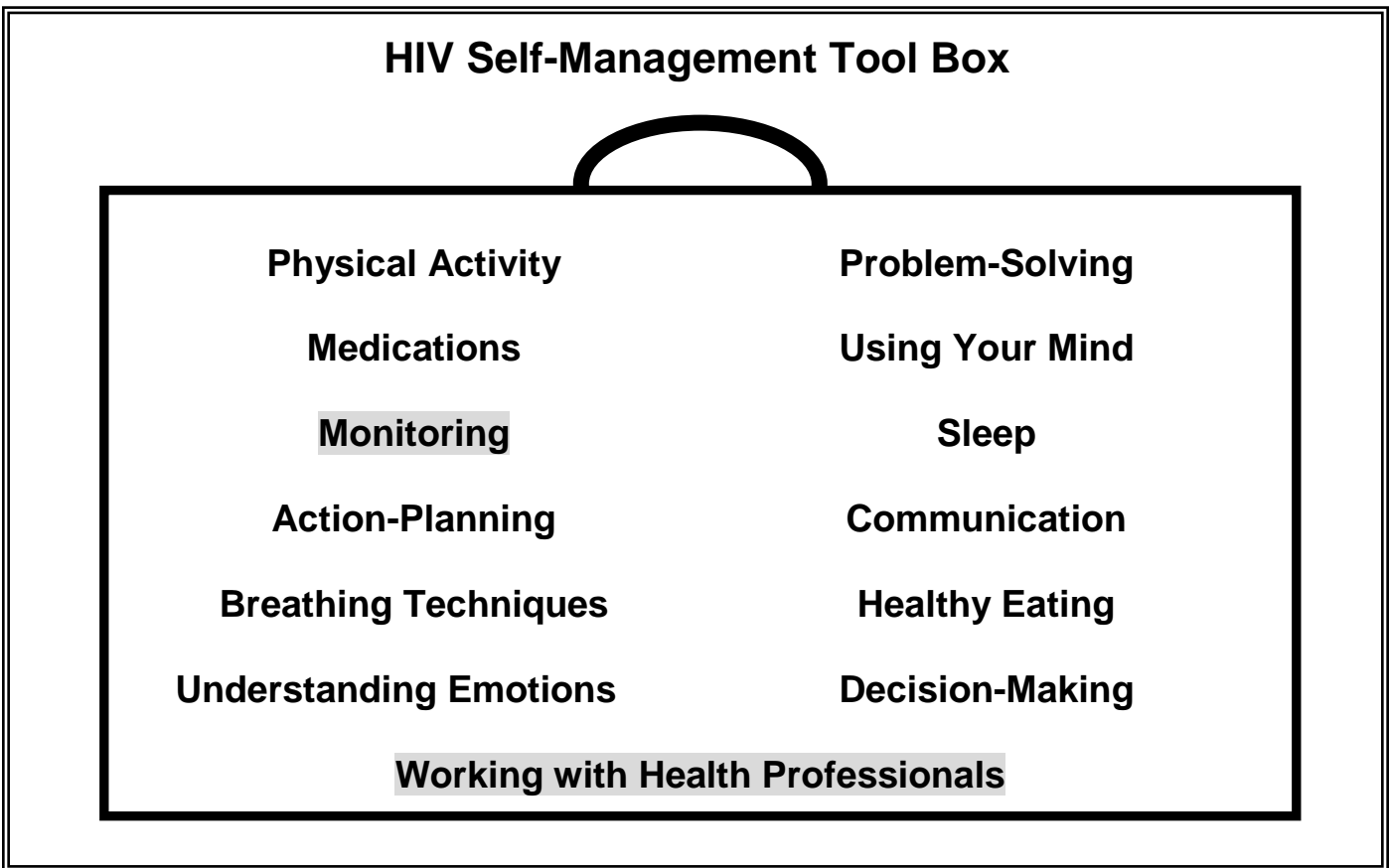
Materials

- Chart 11, “Chris’s Symptoms”
- Chart 12, “Take P.A.R.T.”
- Chart 13, “Do a F.A.S.T. Check”

1. **Say in your own words, pointing to “Working with Health Professionals” on Chart 2:** As we all know, HIV can be a complicated condition, both for the person living with it, and the person’s healthcare team.
 - a. Our healthcare team depends on us to accurately report our symptoms so we can work with them to make decisions.
 - b. However, just reporting symptoms is often not enough.
2. **Say in your own words, pointing to Monitoring on Chart 2:** We must also monitor and report the trend of the condition, as well as what we are doing to manage it on a day-to-day basis:
 - a. Do you have any new symptoms, such as fatigue, depression, or pain from neuropathy?
 - b. Are your symptoms getting better, staying the same, or getting worse?
 - c. Are these changes slow or rapid?
 - d. Has anything in your life changed that may have affected your symptoms?
 - e. What have you done yourself to manage your condition, and did it help?

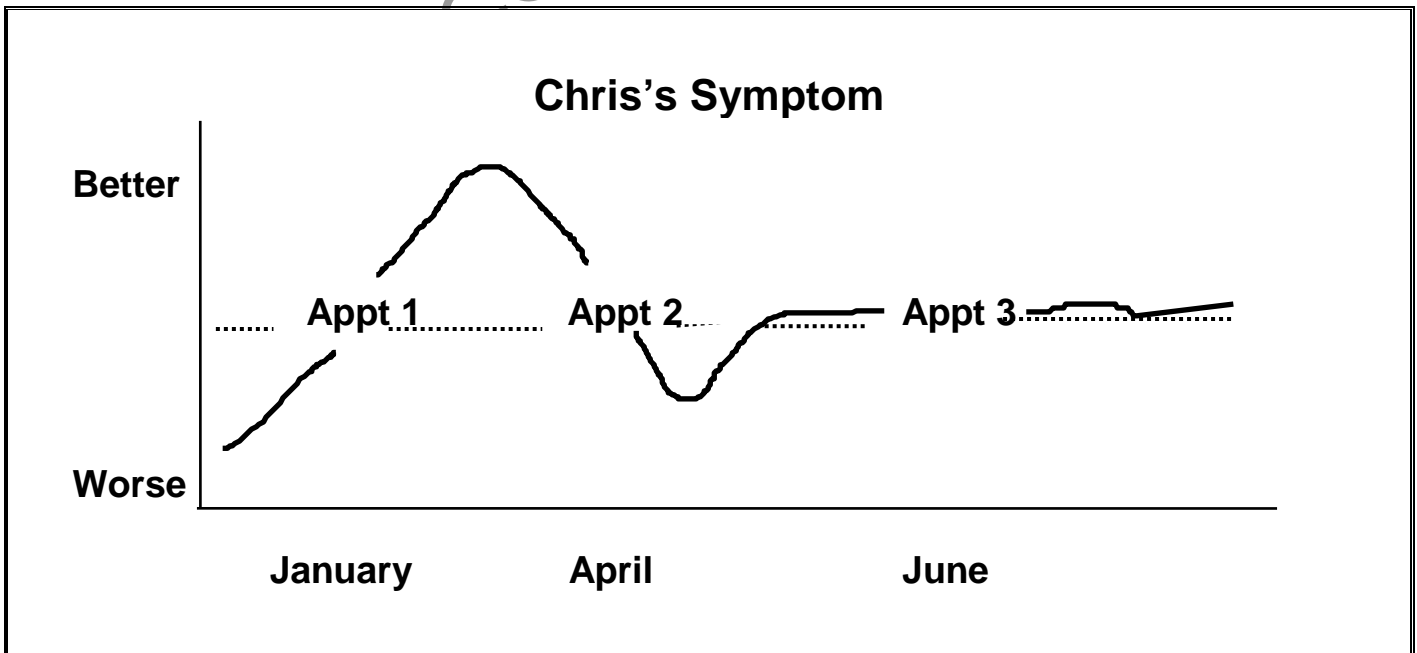
(Chart 2 on the next page)

Chart 2



3. **Say in your own words, pointing to Chart 11:** Most symptoms come and go, get worse and get better, that is, they follow an up and down path.

Chart 11



4. **Say in your own words, pointing at Chart 11:** The visits on this chart are only an example that represent Chris's follow up appointments with the healthcare team. The clinic schedule for people with HIV will vary and is usually every 3-6 months.
- The vertical line on the left side of the chart shows the intensity of the symptom. Better is at the top of the line, and worse is at the bottom.
 - The horizontal line at the bottom of the chart shows when times of Chris's regular follow up appointments at the clinic.
 - The solid line going up and down in the middle of the chart show how bad Chris's symptom is over time. You can see that it was pretty bad but getting better before the January visit, got better and then worse again between the January and April visits, got a little worse and then got better and leveled off between the April and June visits.
 - But the dotted line shows that the Chris's symptom is about the same at each of the appointments.
 - If the doctor asks Chris how he is doing since the last visit and Chris says "about the same" because the symptom is the same as the last visit, the doctor won't have the information that is needed to make decisions about treatment.
 - What has happened in the time between the appointments can mean entirely different things when the healthcare team is evaluating whether to maintain or change the treatment plan.
5. **Instructions to Leaders:** Use an example of your own or use the one provided while explaining the following.

Say in your own words, pointing at Chart 11: Let's say that the symptom giving Chris the most trouble is diarrhea.

- In the case of the January visit, the diarrhea was pretty bad before his appointment. Chris was having many bowel movements a day, and they were very watery. He started using some diarrhea medication, and they were getting better. His bowel movements were not happening as often and they were getting more solid.

At this January appointment, Chris and the doctor decided that they did not need to change his treatment and they might consider backing off on the diarrhea medication a little.

- b. In the case of the April visit, things had been getting better since January, but then they started to get worse again, so additional diarrhea medication may have been the correct choice. Chris and the doctor decided to give things a little longer before considering if one of his HIV medications was to blame and if changing to another was a possible solution.
- c. And, in the case of the June visit, things had gotten a little worse, but then got better and then stayed stable for a while, so maintaining the treatment regimen may have been the best treatment option.

6. **Say in your own words:** Our experience and understanding of how we are doing is often more useful to our healthcare team than any single laboratory test. Without our active participation in the monitoring and reporting of our symptoms, there is no way for our healthcare team to know about the trends of our health problem.

To be most effective, self-management requires that we build a partnership with our healthcare professionals.

7. **Say in your own words:** HIV can be a complicated condition, and given the widening gap between appointments, it is sometimes difficult to keep track of all our symptoms. Keeping a symptom diary can be very helpful in the evaluation of our condition and in making informed decisions about our treatment - both for our healthcare team and ourselves.

This is something you might want to start. Symptom diaries can often be included on medication logs, which is another tool to keep track of your progress.

8. **Say in your own words, pointing at Chart 12:** In order to work effectively with the members of our healthcare team, we can also **Take PART**.

(Chart 12 on the next page)

Take P.A.R.T.

Prepare

- **Keep track** (of your symptoms; monitor what's going on between visits to your provider.)

(For example, are symptoms better, worse or the same; are changes slow or rapid; if anything changed in your life to affect you.)

(Be sure to write this down, along with what you do to manage the symptoms, and whether or not it helped. This will help you spot trends or patterns in your condition. A symptom and medication diary or log can be a very useful tool for recording these things.)

(If you have an online patient portal where you can communicate with your health care team by messaging, you may be able to send this information to your provider ahead of time. Your provider can review them more easily then.)

- **Report** (on your symptoms, changes and patterns in between visits. Also report on any medications or other treatments you are using, and their effects. This can be part of your online message.)

- **List** (your MAIN concerns or questions.)

(Ask these at the beginning of the visit. If you have more than 2 or 3 questions, give the whole list to your provider, but do not expect answers to more than 2 or 3 during this visit.)

(Your provider should see the whole list, however, because something that may not seem important to you may be important medically. This is another time where sending them online before the appointment can be helpful.)

Ask (questions about your diagnosis, tests, medications and follow up.)

Repeat (back to the provider key points discussed during the visit, like diagnosis, what to expect, next steps, treatment actions, etc. This gives both of you an opportunity to correct any miscommunications.)

Take action (If there are barriers to following your provider's recommendations, let the provider know. Ask for written instructions, if appropriate.)

9. **Say in your own words:** Being informed about how to evaluate symptoms is an important part of self-management. As we know, HIV can cause many different kinds of symptoms. Many of these are chronic, like fatigue, anxiety or stress. The best approach to these chronic symptoms is to use self-management strategies.
10. **Say in your own words:** Sometimes, however, a new symptom can be a sign of a new acute infection. Acute conditions often should be handled by seeing the doctor right away. Good self-managers need to know when it's best to apply self-management strategies, and when it is best to seek help from a healthcare professional. We need to know how to **evaluate symptoms**.
11. **Say in your own words, pointing at Chart 13:** To find out whether you should see your doctor about a new symptom, try doing a **FAST Check**.

Chart 13

Do a F.A.S.T. Check
(on new or worsening symptoms)

Fever (*Is the new symptom associated with a Fever?*)

Altered mental status (*Are you unusually spacey, dizzy, or disoriented?*)

Severe (*Is the new symptom a lot more Severe than what you've had in the past?*)

NOT Typical (*Is the new symptom unusual for you?*)

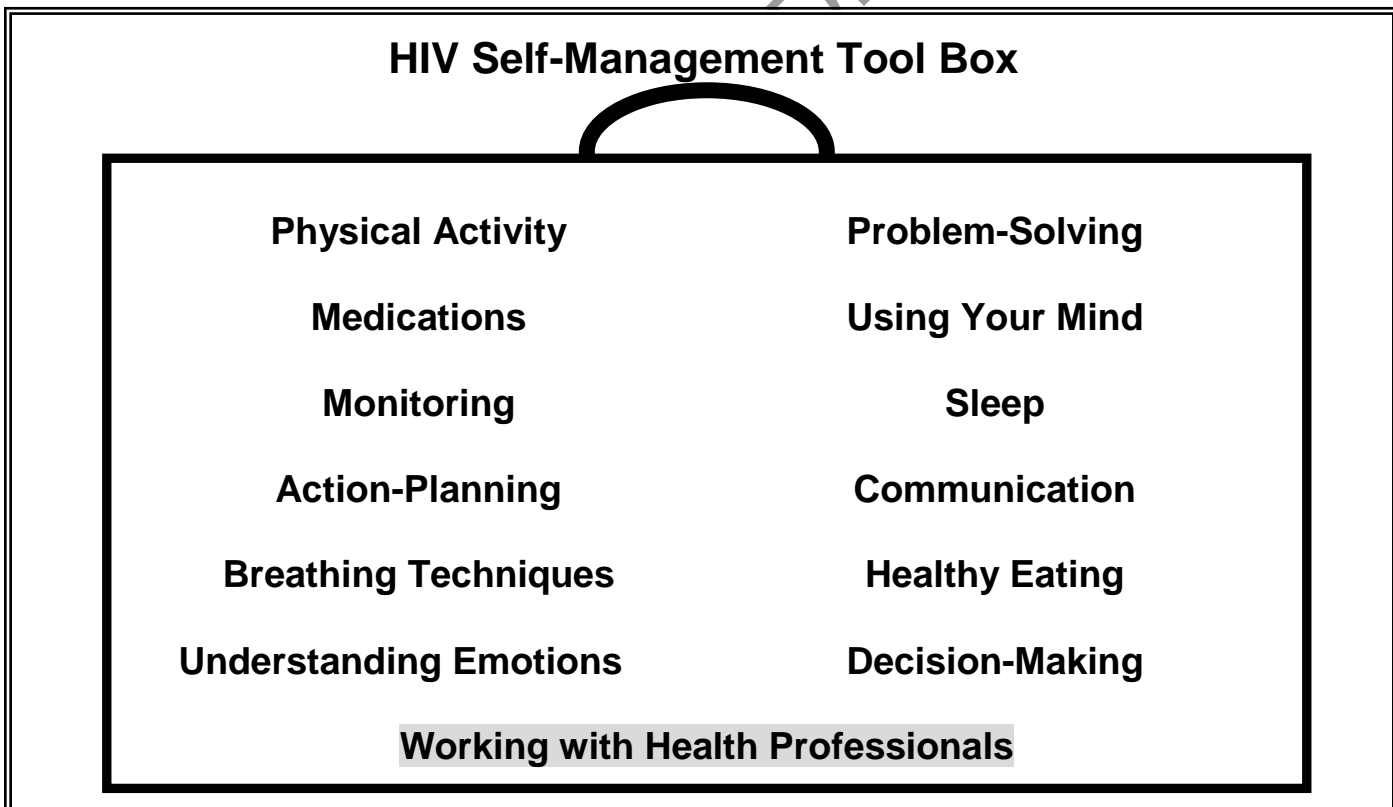
12. **Say in your own words, pointing at Chart 13:** If the answer to any of these questions is YES, the new symptom may be a sign of an acute illness that requires a healthcare provider's attention. Doing this FAST Check can help you determine when a symptom should be checked out by a healthcare provider.
13. **Say in your own words:** However, if your symptom is chest pain or numbness on one side of the body, or having trouble breathing, get medical help right away. These can be signs of heart attack or stroke. Don't wait. Call 9-1-1.

14. **Instructions to Leaders:** Ask volunteers to think of examples of times when they have experienced new symptoms. Ask them how they would have applied the FAST Check to these circumstances. Ask them whether or not they think they should have seen a healthcare provider, and whether they actually did. **(NOTE: Leaders should have some examples of their own ready.)**



15. **Say in your own words, while holding up page 123 in the book:** If you look at page 123 in your book, you will find detailed information about a specific symptom, cough, and a flow chart that helps you determine when to use self-management techniques and when to seek medical attention. This chapter also has symptom action charts for other symptoms, as well.
16. **Say in your own words, pointing to “Working with Health Professionals” on Chart 2:** Remember, “Working with Health Professionals” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



17. **Say in your own words:** When dealing with HIV medication, we work in partnership with our health professionals. We will talk about this next.

Activity 3

TAKING HIV MEDICATION (ART)

20 minutes

Materials

- Chart 14 “Taking HIV Medications”

Note to Leaders

The main purpose of this activity is to provide a little information about Anti-Retroviral Therapy (ART), and to support those participants who are taking or about to take ART.

Leaders are not expected to be treatment experts.

However, it is helpful to familiarize yourself with the information in the *Living a Healthy Life with HIV* book, and with other available resources, prior to leading this activity.

Also, encourage participants to seek out more information on their own and from one another. This is part of effective HIV self-management.

It is suggested that your program coordinator place examples of medication and symptom logs on the resource table.

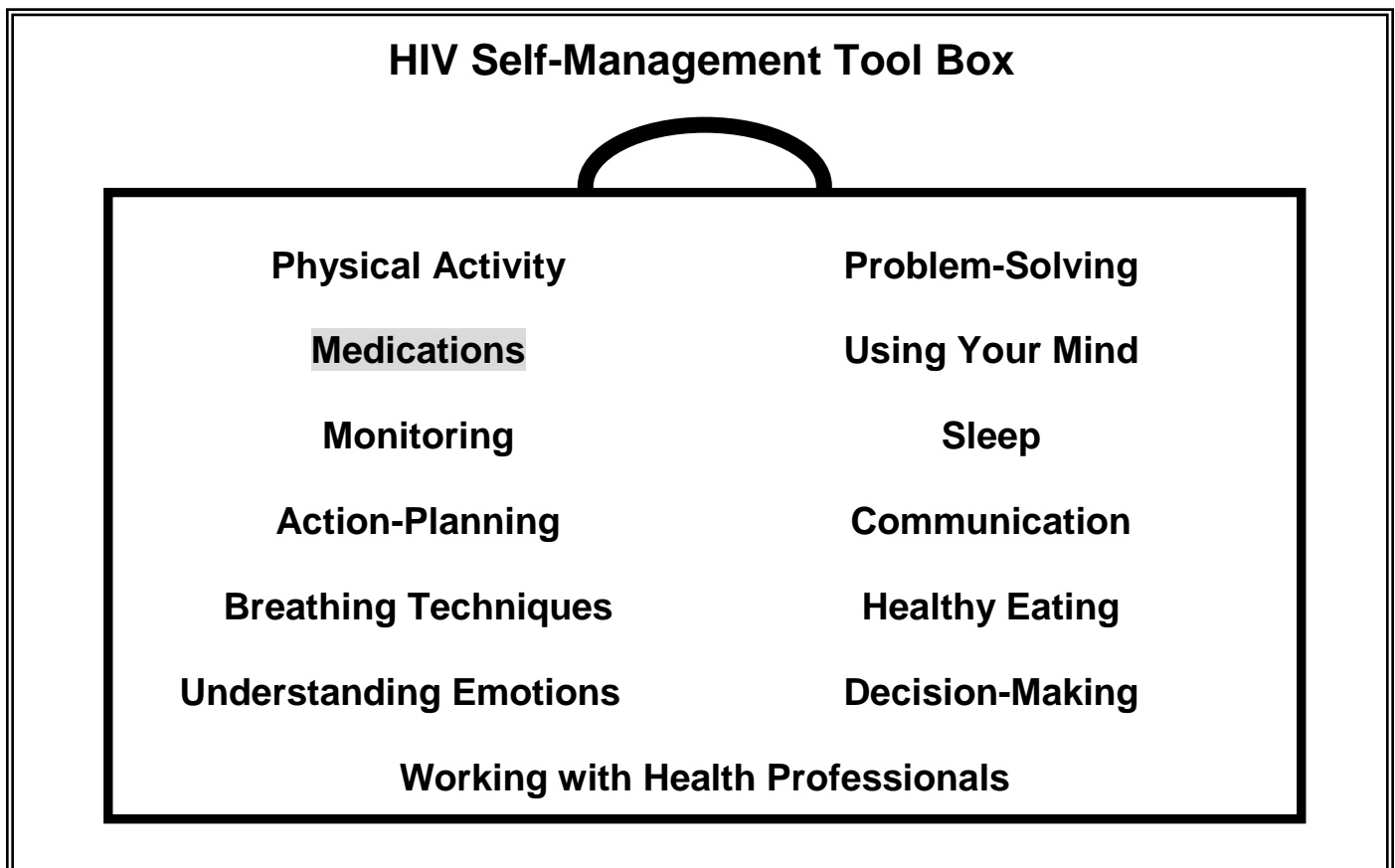
1. **Say in your own words, pointing to “Medications” on Chart 2:** HIV treatment has changed dramatically from the early days of the epidemic. There are now many more medications available to help people living with HIV, and more are being developed all the time.

Knowledge about medications is changing all the time. You may hear new information about a drug you are familiar with, about a medication that you haven’t heard about, or a new experimental treatment.

If you are confused by anything having to do with medications, talk to your healthcare provider or pharmacist. Pharmacists are very knowledgeable resources and are readily available to answer your questions.

(Chart 2 on the next page)

Chart 2



2. **Say in your own words:** These drugs cannot kill the virus, but they can lower the amount of HIV in your body by slowing down its rate of replication (making more copies of itself). These drugs are referred to as anti-retrovirals, anti-HIV drugs, or HIV antiviral drugs.
3. **Say in your own words:** For treatment to be effective for a long time, research has found that we need to take more than one anti-HIV drug at a time.

This is what is known as **Combination Therapy** or sometimes **Anti-Retroviral Therapy**, shortened to **ART**. This usually consists of two or more drugs, though many drugs these days are taken as a single combination pill.

New research being conducted now may change this, though, and we may find a different medication landscape in 2 or 3 years.

4. **Say in your own words:** Even though in recent years HIV treatments have become much more effective and simpler to use, there are still important facts about these medicines that need to be considered by anyone taking them or about to take them.

- a. Anti-HIV drugs need to be used in combinations. Sometimes this makes them complicated to use because different drugs may have to be taken at different times of the day. At the beginning of treatment, though, it could be as easy as one pill once a day, since some medications have been combined into a single tablet. Examples of one pill that combines multiple antiretroviral drugs are Triumeq or Stribild.
- b. You need to adhere to the drug schedule you are given. **Adherence** means that once you and your doctor have decided that you will use a certain combination of HIV drugs **YOU WILL TAKE THEM EXACTLY AS THEY HAVE BEEN PRESCRIBED**. Adherence is very important because...
- c. Using only one medicine that is not in a combination tablet by itself, or not taking the drugs in their prescribed combinations may be worse than doing nothing at all.

People who do not properly follow their drug schedule can develop drug-resistant HIV. Resistance means that that drug won't work against the virus any longer.

The newer combination tablets can make this much simpler to stay on schedule, though.

- d. It's very important that you follow your doctor's guidance, and that you do not miss any pills – whether by forgetting, intentionally skipping, lowering the dose, or changing the times you take them.

Taking them on schedule helps reduce the risk of developing resistance to the drug.

If you find that you're having problems sticking to your drug schedule for any reason, you need to discuss this with your doctor immediately. It's especially important that you contact your doctor if you are experiencing drug-related side effects, rather than just stopping the pills.

5. **Say in your own words:** As with any other chronic health condition, medications are an important part of our treatment program, but each person needs to decide, along with their healthcare provider, whether or not a medicine is right for them, as well as which ones they should use at a given time.

- a. Sometimes there can be drug interactions, side effects, or resistance. And although more pills are now being made that combine two or more drugs, taking ART can still be a challenge, especially at the beginning.
 - b. Please note that a lot of people take these treatments with little or no side effects, and that these side effects usually subside after a few weeks.
6. **Say in your own words, pointing to Chart 14:** There are some points to consider when taking ART.

(Chart 14 on the next page)

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Taking HIV Medications

- 1. Remembering to take them** (*What is your day like? Do you work? Do you have meetings? Do you travel a lot? Do you get so involved in what you are doing that you lose track of time? Are you able to go for regular blood tests? Are you sometimes just forgetful?*)
- 2. Flexibility to schedule them** (*Some medications need to be taken with food, but some may need to be taken on an empty stomach. Do you have any dietary restraints due to other health problems? Some medications cannot be taken with supplements such as calcium. Are there other reasons?*)
- 3. Fitting into your lifestyle** (*Do you travel a lot across time zones? Work night shifts? Work unpredictable hours? Do members of your household know you're HIV positive, or have you chosen not to tell them? Do you have a different weekend routine? Do you have problems with alcohol or other substance addiction?*)
- 4. Possible changes to current therapies** (*Some may be dangerous or reduce the effect of the drug if taken with ART, including some alternative therapies and supplements. Supplements can be vitamins, protein, herbs, steroids, and so on*)
(It is very important to tell your healthcare providers about ALL therapies, supplements and over the counter medicines you are taking or considering, such as medical marijuana and calcium because they can affect absorption of your HIV medications.)
- 5. Possible side effects** (*Like many other medications, side effects may occur, particularly when starting a new regimen. How will side effects affect you? If you have bad side effects will you be able to take time off work? Side effects may pass in a week or so but keep your health professional informed.*)
- 6. Support in place** (*to maintain this therapy. Help of family, partner, co-workers, and community services. It sometimes can be difficult to maintain these medications all by yourself!*)
- 7. Making it right for you** (*Will you be embarrassed to take them when you are out? How will it feel to be reminded that you have HIV every time you take your pills? What is happening in your life, such as holidays, social commitments, work and so on?*)
- 8. Ready to commit** (*You must be willing and committed to do it!*)

7. **Say in your own words:** As you can see, there is a lot to consider when taking HIV medications. You may want to use the decision-making tools we learned last week as part of your consideration process.

Brainstorming Guidelines for Leaders

- The facilitator reads the question as written in the manual.
- The scribe writes the brainstorm question, using KEY words.
- The facilitator repeats the ideas loudly, using the participant's own KEY words while looking at group, not at the scribe.
- If the idea is too long, ask the participant to shorten it. If they cannot, ask for permission from them if you shorten or rephrase it.
- The scribe listens only to the co-Leader and writes what the facilitator says.
- The scribe does not use abbreviations or symbols.
- The scribe is responsible for telling the facilitator if they can't keep up with the ideas.
- The facilitator controls the "traffic"- slowing the brainstorm if the scribe needs to catch up.
- Neither the facilitator nor the scribe comment or allow anyone else to comment on the ideas (positively or negatively, verbally or by facial expression).
- The facilitator does not allow questions until after the brainstorm is over.
- If there are fewer than 15 ideas, the facilitator uses silence **...W...A...I...T...!** (it's not over until you have counted to 15 to yourself with no new ideas). If there are no more, the brainstorm is over.
- The facilitator does NOT call on people.
- The scribe tells the facilitator when there are 15 ideas listed.
- If there are 15 ideas, the facilitator tells the group you will take 2 more and end the brainstorm.
- After the brainstorm, the scribe or facilitator reads back the list to the group.
- The facilitator asks if any ideas need clarification.
- If there are ideas listed in the manual to add, the facilitator adds only those ideas that are not already listed.
- If any ideas are "inappropriate", such as alcohol or violence, the facilitator points this out politely without pointing anyone out.

8. **Say in your own words:** Having support is one thing that is very important to ensure that these medications are successful.

Let's brainstorm. Here's the question we are going to brainstorm.

What kinds of skills, resources, or help does a person need to be successful in taking ART?



9. **Instructions to Leaders:** When they are finished, read back the list and ask for clarification. Be sure to add any of the following bulleted items if they are not mentioned.

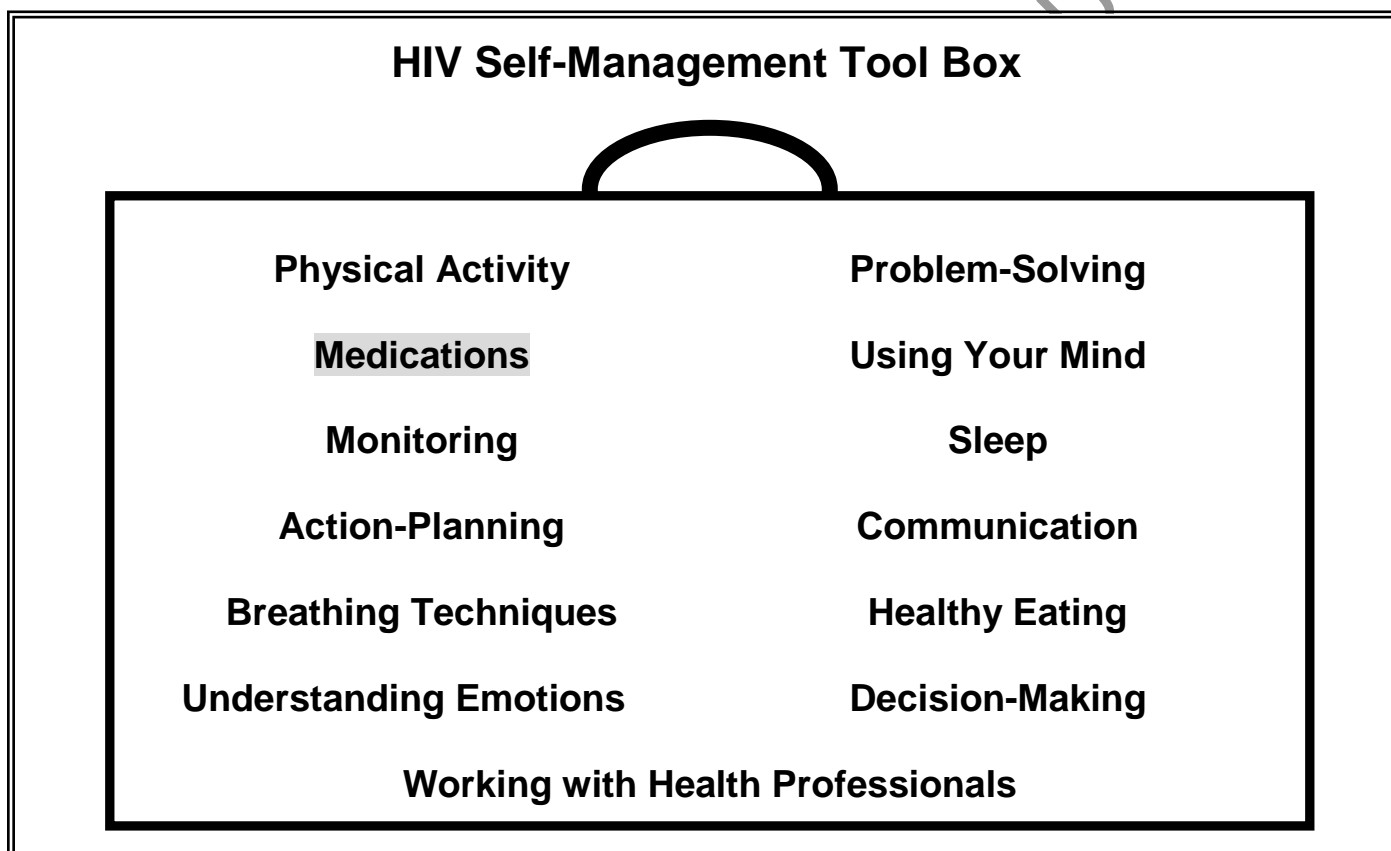
- a. Physical resources to help us store and organize the medications, such as
- A medicine cabinet at home or other secure storage space
 - Pill boxes for storing or travel
 - Daily logs or alarms to help us remember if we take them.
- b. Social resources, such as
- Support from the important people in our lives for helping us to stay on the medication schedule
 - Community resources, such as support groups.
- c. Information about the medications and all their side effects, dosage and storage requirements, or we need to know where to find this information.

10. **Say in your own words:** Please look in your *Living a Healthy Life with HIV* book for more information about HIV medications, including common side effects for specific drugs. The pages are listed on your homework handout.
11. **Say in your own words:** We suggest that anyone on ART keep track of their medications. The log can also be combined with the symptom diary that we discussed last week. There are many types of logs or diaries available from your clinic or online. You may also find an app for your smart phone to keep track. We suggest you start one this week, if you haven't already. [Instructions to Leaders: Refer to resource table if examples are provided by your program coordinator.]
12. **Say in your own words:** It is a good idea to keep a copy of your medication list in a visible place, in case you have an emergency and the EMTs need your list. Keeping the list plus your advance health care documents on or in your

refrigerator makes it easy for them to find in an emergency. We'll be talking about advance health care directives in Session 5.

13. **Say in your own words:** Your healthcare team can give you more information if you need it. But remember, **YOU** are an expert on **YOUR OWN** experience, resources, attitudes, priorities, and skills. After the break, we will explore this topic more by doing some problem-solving.
14. **Say in your own words, pointing to “Medications” on Chart 2:** Remember, “Medications” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



15. **Say in your own words:** Let's take a 20-minute break now. When we come back, we will work on solving some problems together.



BREAK

20 minutes

Activity 4

PROBLEM-SOLVING

30 minutes

Materials

- Chart 7, “Problem-Solving Steps”

1. **Say in your own words:** Having HIV can present problems and challenges in our everyday lives. These can range from not being able to stick to our medication schedule on weekends, to being unable to keep up with family and friends, to being embarrassed because we need to take medication away from home.
2. **Say in your own words, using Chart 7:** Now we will have an opportunity to practice our problem-solving skills, and share with and help each other at the same time. We’re going to break into pairs and use the first 3 problem-solving steps to work on any problem we have. In your pairs you will:
 - a. First, identify the problem you have experienced lately but haven’t solved.
 - b. Next, brainstorm some solutions with your partner.
 - c. And finally, choose a solution that you are going to try.

Chart 7

Problem-Solving Steps

1. **Identify the problem**
2. **List ideas**
3. **Select one**
4. **Assess the results**
5. **Substitute another idea**
6. **Utilize other resources**
7. **Accept that the problem may not be solvable now**

3. **Say in your own words:** Each of you will have about 5 minutes to work on your problem. At the end of 10 minutes we will get back together, and each person will report on their **partner’s** problem and solution.

If you don't want something shared with the whole group, either don't tell your partner about it or ask your partner not to discuss this with the group.

4. **Say in your own words:** Please break up into pairs. People with HIV should pair up with each other and significant others or support members should pair up with each other. You should *not* pair with the person you came with.

We will let you know at the halfway point and then again, a minute before we come back together as a group.

5. **Instructions to Leaders:** One Leader should keep time, letting people know at 5 minutes that half their time is up. Don't let the sharing go longer than 10 minutes.

Reconvene the group.

6. **Say in your own words:** We would like each person to report **concisely** on:

- **Your partner's** problem
- One or 2 solutions you came up with
- Which solution your partner will try
- Please keep your reports short

7. **Instructions to Leaders:** Ask for a volunteer to start, then their partner, next go around the room. Don't ask for volunteers after the first pair.

At the end of each report, check with the partner to see that the report was correct, but don't allow the person to go into a lengthy "story;" **remind people to be concise in their reports.**

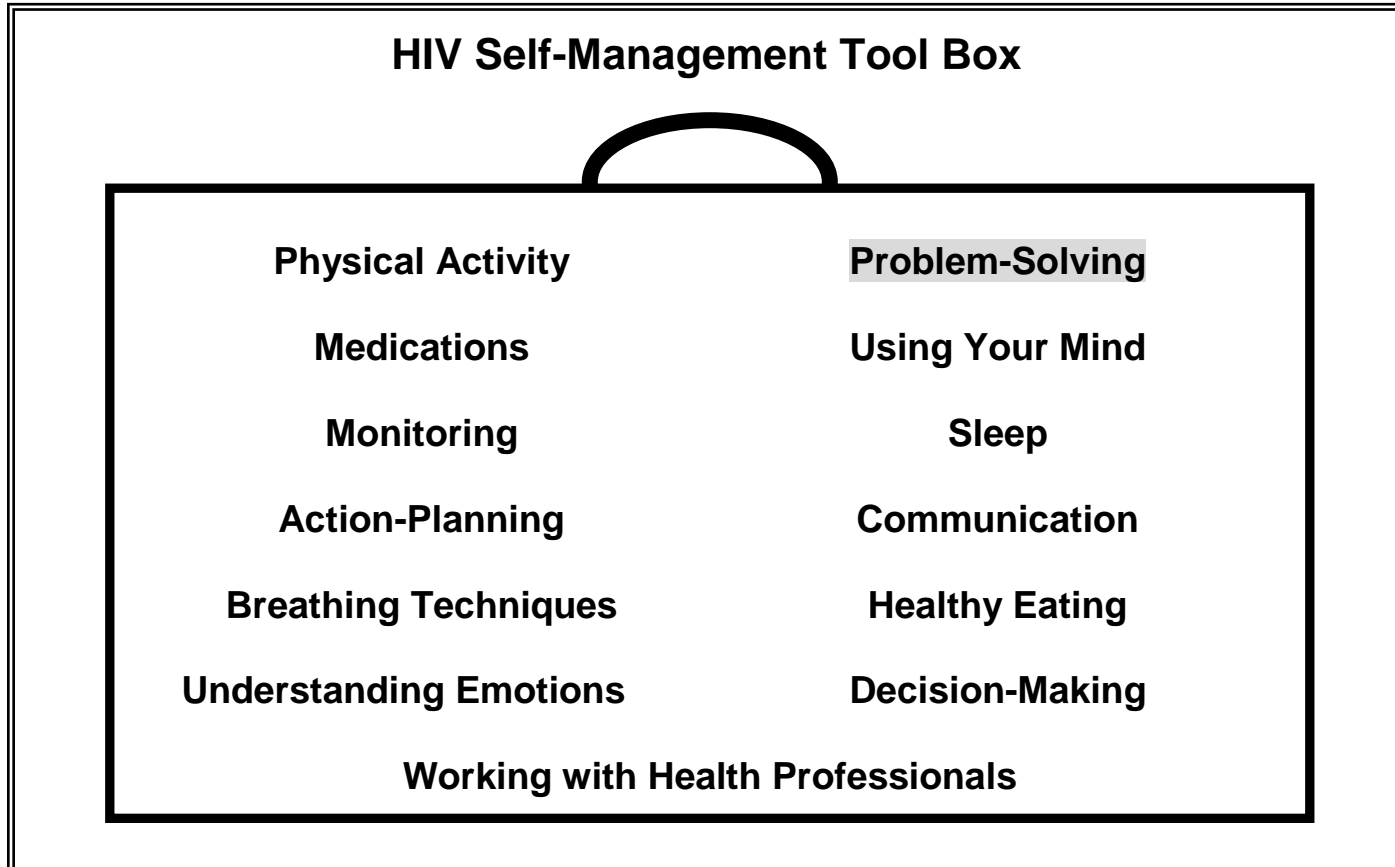
8. **Instructions to Leaders:** After all the pairs have shared, ask participants by a show of hands if anyone heard new solutions during the reports that they might add to their own list or might find useful in the future.

9. **Instructions to Leaders:** Ask participants **how it felt to help another person** solve problems. Point out that everyone, even those of us with problems of our own, can be helpful to others in this and other ways.

10. **Instructions to Leaders, pointing to "Problem-Solving" on Chart 2:**
Problem-solving is one of our most important self-management tools in the Tool

Box. It enables us to use all the other skills and tools we have learned in the most effective ways.

Chart 2



11. **Say in your own words:** Now will take some time to learn how to relax.

Activity 5 15 minutes

BETTER BREATHING AND RELAXATION BODY SCAN

Materials

- Chart 2, "Self-Management Tool Box"
- Chart 8, "Symptom Cycle"
- Relaxation CD (optional)
- CD player (optional)

Note to Leaders

Sometimes participants object to this and other cognitive techniques for religious or other personal reasons. If this occurs, the participant should be excused from the activity. They may choose to leave the room, pray, or sit quietly during the activity.

Cognitive techniques should be pleasant or boring, but never frightening or physically painful. If participants are uncomfortable or frightened, they should be urged not to use the technique.

If someone falls asleep, one leader should touch them lightly to awaken them, if culturally appropriate.

1. **Say in your own words, pointing to Stress/Anxiety and Tense Muscles on Chart 8:** Sometimes when we rest, we don't really get good quality rest because our minds keep racing, our muscles are tense, and we just cannot seem to relax. The good news is that we can learn relaxation techniques that can help soften our muscles and quiet our mind.

Chart 8

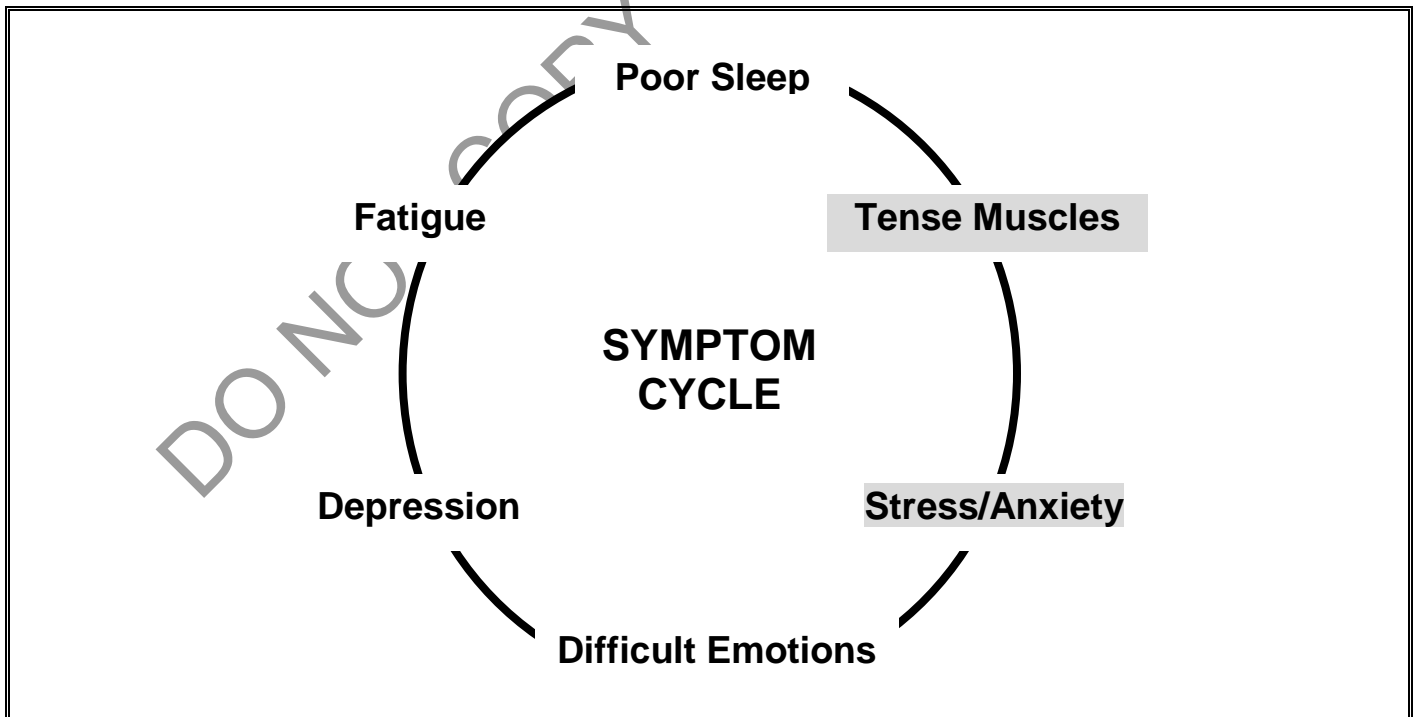
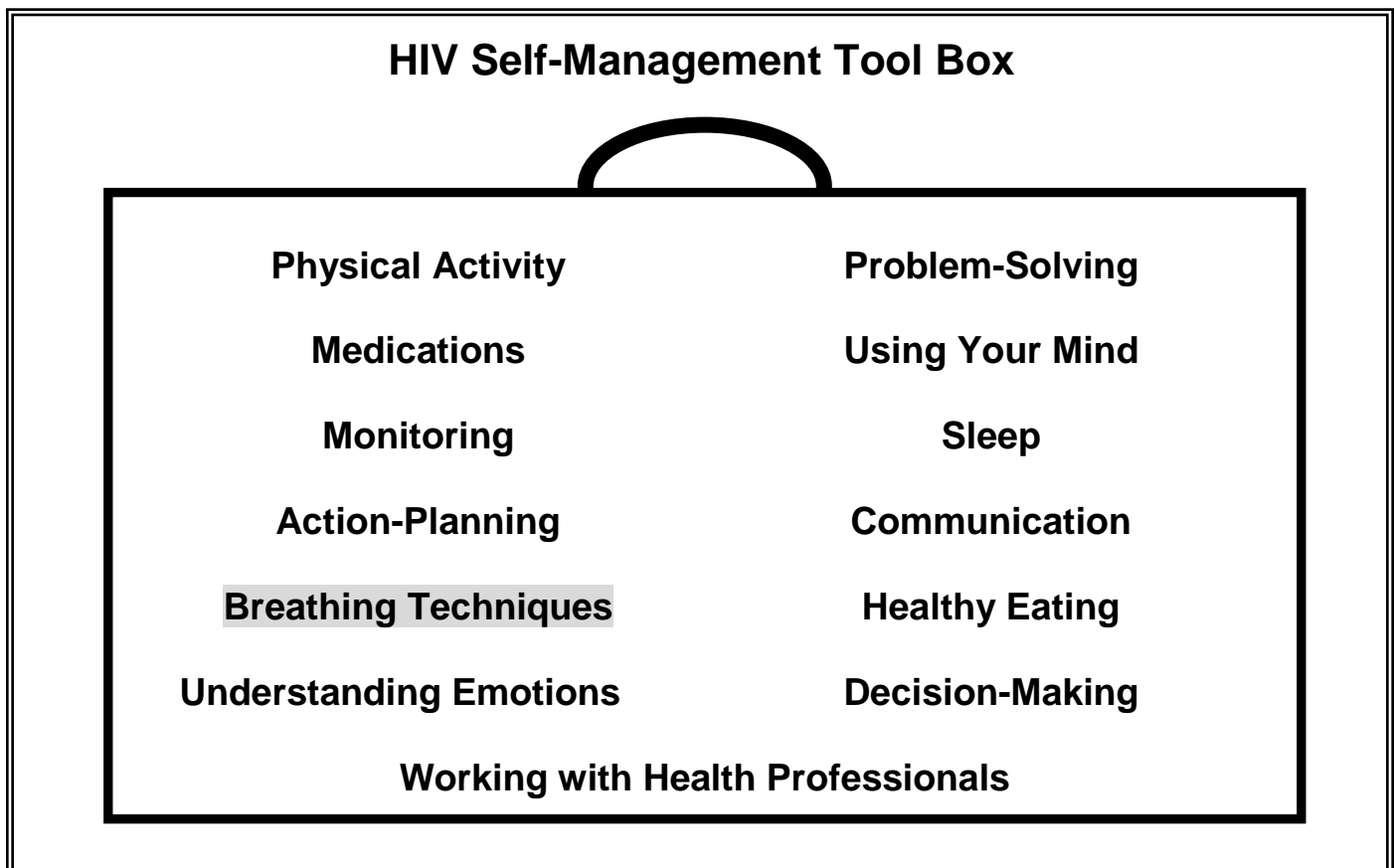


Chart 2



2. **Say in your own words, pointing to “Breathing Techniques” on Chart 2:** The first step in learning to relax is to focus on and practice better breathing. Better breathing energizes both the mind and body and it’s something everyone can do.
- The easiest technique for all of us to use is **pursed-lip breathing**, which helps us to empty our lungs of used air by exhaling slowly and completely through the mouth.
 - Then there is **diaphragmatic or belly breathing**; the name comes from the diaphragm, which is the muscle below the chest that is used for **deep** breathing. We sometimes call this belly breathing because when it is done correctly your belly moves.
 - Belly breathing is particularly helpful when we are feeling stressed and anxious because it increases the oxygen we take in and enhances the relaxation response. My partner and I are going to demonstrate a combination of these two types of breathing. Please do them with us.

Breathing Guidelines for Leaders

Find a comfortable position either standing or sitting. (This can also be done lying down, which is the easiest position for beginners or those having difficulty.) Be sure to relax your shoulders.

Place one hand on your abdomen just above your belly button and below your breastbone, and the other hand on your upper chest.

Breathe in through your nose. (If you can't breathe in through your nose, then breathe in through your mouth.) As you breathe in you should feel your abdomen expanding. At the same time, you should feel only a little movement in the upper chest area.

Next, purse your lips gently, as if you were going to whistle. Now breathe out slowly through your pursed lips, while at the same time you gently contract your abdominal muscles. Let the air flow out slowly, **DO NOT** force it out. It should take you twice as long to exhale as it does to inhale. If you feel lightheaded, you are breathing out too fast.

- 3. Instruction to Leaders: Demonstrate pursed-lip breathing and diaphragmatic or belly breathing. Ask everyone to breathe with you.** Emphasize that these breathing skills can be used by everyone especially when feeling stressed and when we need to relax.

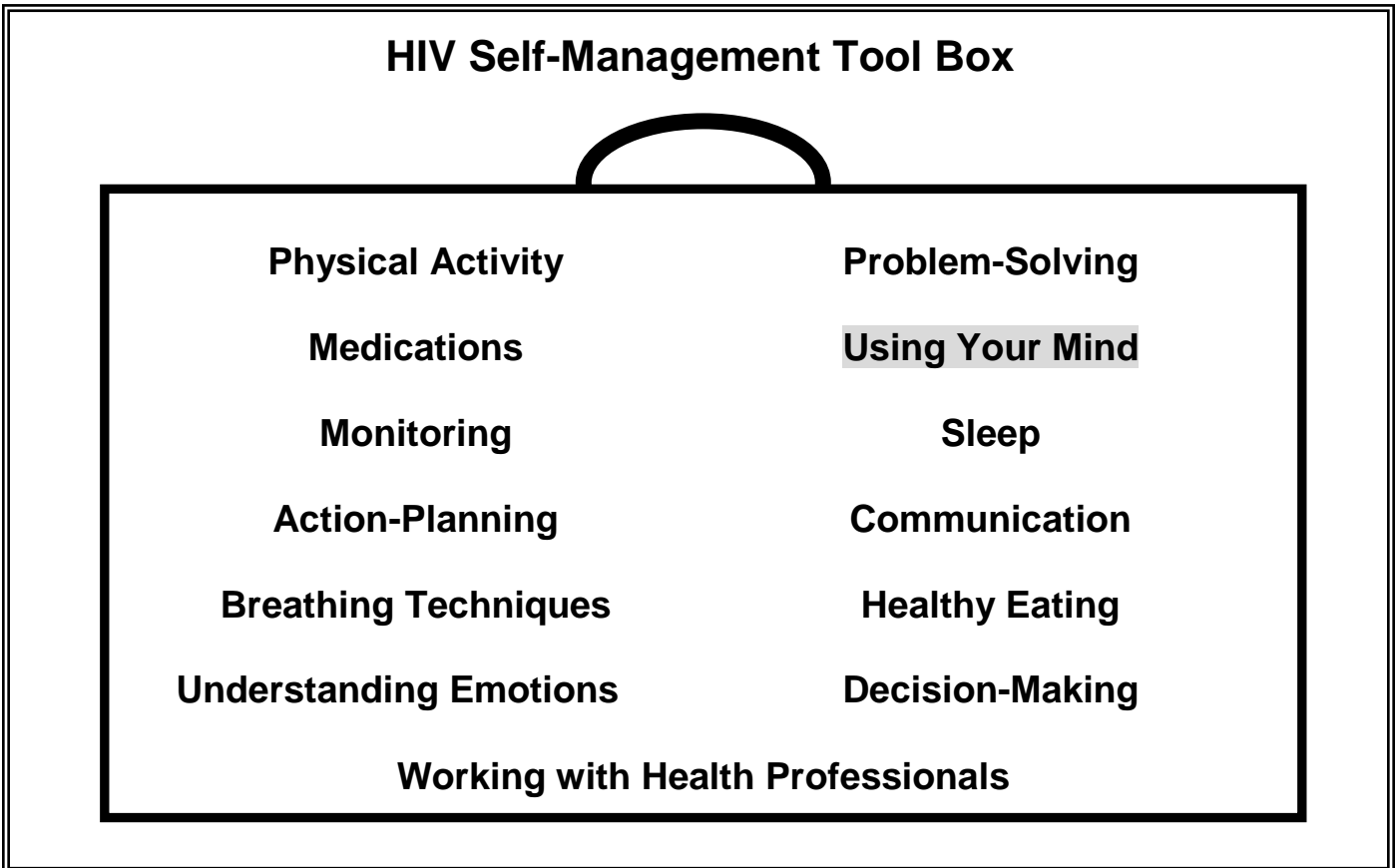
IMPORTANT
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- 4. Say in your own words:** Sometimes people try to hurry through activities in order to finish before their pain increases or they run out of breath. This is not helpful. Slow down and take some deep breaths.
- 5. Say in your own words:** Better breathing is also very important both in preparation for and during several relaxation techniques. Now, we are going to use better breathing with a relaxation exercise called “Body Scan”.
- 6. Say in your own words, pointing to “Using Your Mind” on Chart 2:** The first step in doing this is to focus on your breathing, then to scan your body for tension in order to release it with your breath. This technique relaxes not only the mind but also the muscles.

The Body Scan is one of the thinking techniques in our Tool Box, under Using Your Mind, which we are going to practice now.

Chart 2



7. Instruction to Leaders: Lead the group through the Body Scan Relaxation, using the CD or reading the script. If reading the script, remember to pause for a few seconds when you see the series of dots (. . .) and between paragraphs

Body Scan Relaxation

As you get into a comfortable position, allowing yourself to begin to sink comfortably into the surface below you, you may perhaps begin to allow your eyes gradually to close... From there, turn your attention to your breath... Breathing in, allowing the breath gradually to go all the way down to your belly... and then breathing out...And again, breathing in...and out... noticing the natural rhythm of your breathing...

Now allowing your attention to focus on your feet. Starting with your toes, notice whatever sensations are there--warmth, coolness, whatever's there...simply feel it. Using your mind's eye, imagine that as you breathe in, the breath goes all the way

down into your toes, bringing with it new refreshing air...And now noticing the sensations elsewhere in your feet... not judging or thinking about what you're feeling, but simply becoming aware of the experience of your feet as you allow yourself to be fully supported by the surface below you...

Next focus on your lower legs and knees. These muscles and joints do a lot of work for us, but often we don't give them the attention they deserve. So now breathe down into the knees, calves, and ankles, noticing whatever sensations appear...See if you can simply stay with the sensations...breathing in new fresh air, and as you exhale, releasing tension and stress and allowing the muscles to relax and soften...

Now move your attention to the muscles, bones, and joints of the thighs, buttocks, and hips... breathing down into the upper legs, noticing whatever sensations you experience. It may be warmth, coolness, a heaviness or lightness. You may become aware of the contact with the surface beneath you, or perhaps the pulsing of your blood. Whatever's there... what matters is that you are taking time to learn to relax...deeper and deeper, as you breathe...in...and out.

Move your attention now to your back and chest. Feeling the breath fill the abdomen and chest... Noticing whatever sensations are there... not judging or thinking, but simply observing what is right here right now, allowing the fresh air to nourish the muscles, bones, and joints as you breathe in, and then exhaling any tension and stress.

Now focus on the neck, shoulders, arms, and hands...inhaling down through the neck and shoulders, all the way down to the fingertips. Not trying too hard to relax, but simply becoming aware of your experience of these parts of your body in the present moment...

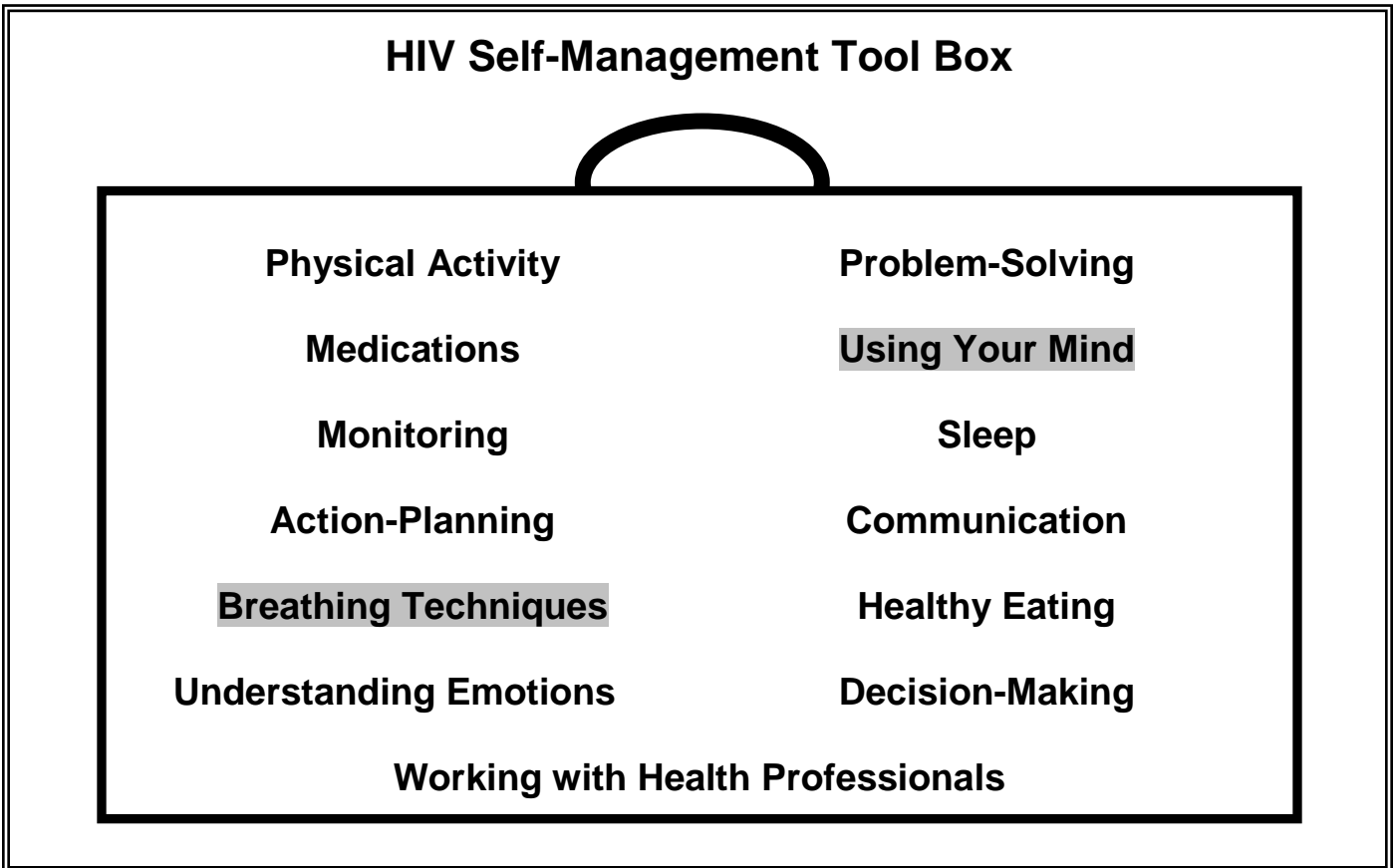
Turning now to your face and head, notice the sensations beginning at the back of your head, up along your scalp, and down into your forehead...Then become aware of the sensations in and around your eyes and down into your cheeks and jaw... Continue to allow your muscles to release and soften as you breathe in nourishing fresh air, and allow tension and stress to leave as you breathe out...

As you drink in fresh air, allow it to spread throughout your body, from the soles of your feet all the way up through the top of your head... And then exhale any remaining stress and tension... and now take a few moments to enjoy the stillness as you breathe in... and out... Awake, relaxed, and still...

Now as the body scan comes to a close, coming back into the room, bringing with you whatever sensations of relaxation...comfort...peace, whatever's there... knowing that you can repeat this exercise at any appropriate time and place of your choosing... And when you're ready open your eyes.

8. **Say in your own words:** As with any new skill, we need to give this a good try - at least 3 to 4 times a week in the next 2 weeks, for example - before deciding whether or not we like it.
9. **Instruction to Leaders:** Inform the participants that the script is also printed in *Living a Healthy Life with HIV*. In addition to the script in the book, the relaxation CD also has both a long and short version of this exercise, should they prefer to use a CD. The CD also includes 2 guided imagery scripts that they may wish to try.
10. **Instruction to Leaders:** Suggest that they might consider trying the body scan as part of a rest period or when cooling down after exercise. It can also be helpful in relieving pain, helping sleep or combating fatigue.
11. **Say in your own words, pointing to “Breathing Techniques” and “Using Your Mind” on Chart 2:** Remember, “Breathing Techniques” and “Using Your Mind” are 2 of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



Activity 6

MAKING AN ACTION PLAN

15 minutes

Materials

- Chart 6, “Parts of an Action Plan”
- Action Plan Flow Chart, Appendix II

1. **Say in your own words:** Now it’s time to make our action plans for this week. This is something we will do each week.

Remember that action plans allow us to achieve what we want or decide to do by breaking down the activity into smaller, more “doable” steps or tasks.

2. **Say:** Let’s briefly review the parts of an action plan:

Parts of an Action Plan

1. **Something YOU want or decide to do**
2. **Achievable** (*something you can expect to be able to do this week*)
3. **Action-specific** (*for example, losing weight is not an action or behavior, but replacing snacks with fruit between meals is; losing weight is the RESULT of actions*)
4. **Answer the questions:**
 - What? (specific action)**
 - How much? (time, distance, amount)**
 - When? (time of day or which days of the week)**
 - How often? (number of days in the week) avoid "every day"**
5. **Confidence level of 7 or more** (*On a scale of 0=not at all sure to 10=totally sure*)

3. **Say in your own words:** We'll start with our own action plans for the week.

4. **Instructions to Leaders: One Leader should go through each step on Chart 6 (pointing at each step while standing next to it), using their own action plan. Start by saying what you are trying to accomplish such as exercise more.**

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PREPARE BEFORE SESSION: Leaders should prepare action plans in advance with each other, remembering that the Leaders' action plans will be **MODELS** for the rest of the participants. This means that your action plan should be something you really want to do and will complete.

If possible, at least one Leader's action plan should be around behaviors taught in the workshop (e.g., exercise, distraction, or relaxation techniques). Also, it should appear reasonable to the participants. (For example, even if you walk 5 miles a day, tailor your action plan so it is not too intimidating to the group. Make a plan for a half a mile a day instead.)

Leaders should make action plans around different things, for example, one might be about exercise, and the other about relaxation. Be careful to make the

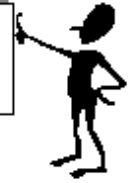
action plan for 3-4 times a week, rather than 5-7, and report a confidence level of 7-9.

5. **Say in your own words:** Now my partner will share their plan.

Instructions to Leaders:

The second Leader reports their action plan, answering each of the questions on Chart 6 as the first Leader points to them.

IMPORTANT
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6. **Instructions to Leaders:** Emphasize that action plans must be:

- something you *want or decide to do*
- *achievable*, that is you can expect to achieve it in the next week

7. **Say in your own words:** Please tell us your action plan for this week, and how sure you are that you will complete the plan, 0 being not at all sure and 10 being totally sure.

8. **Instructions to Leaders:** Ask for a volunteer to start reporting action plans and then go around the room from that person (do not ask for a second volunteer).

Point to each step (what, how much, when, how often, confidence level) on Chart 6 as each participant reports their plan.

See Appendix II, Making an Action Plan Flow Chart

9. **Instructions to Leaders:** If confidence level is less than 7, ask the participant what the problem might be and if they encounter the problem, what would they do.



Ask the participant if they would like suggestions from the group.

If they say yes, have the group offer 4-5 suggestions and the original participant should not comment.

After all the comments ask the participant “if you have (name the problem) what will you do?” Participants can change the plan if they wish.

Ask the participant to state the new or amended action plan, starting with “I will”.

To help people make an action plan, refer to the Making An Action Plan Flow Chart in Appendix II.

- 10. Instructions to Leaders:** If someone is having trouble writing a clear action plan (i.e., specific activity, times per day, days per week), go through the same steps as above, **asking other group members for suggestions** *before* you help.

Do not spend more than 3 minutes with any one person. If someone is having problems, work with them individually *afterwards*.

If someone does not want to make an action plan say that is OK and that you will come back to them later—then go back to the person after everyone has made their plan. If they still do not want to make a plan that is OK.

NOTE TO LEADERS: See Making an Action Plan Flow Chart in Appendix II for details on how to help someone make an action plan.

Activity 7

CLOSING

5 minutes

- 1. Instructions to Leaders:** Remind participants that they may want to start a medication log or symptom diary. More information is in the book.
- 2. Instructions to Leaders:** Encourage participants to review what was covered today in *Living a Healthy Life with HIV*. The reading for each session is listed on the back of their “Workshop Overview” handout.
- 3. Say in your own words:** Next week, we will be discussing **depression management, sex, intimacy and telling others, communication skills, and exercise.**
- 4. Instructions to Leaders:** Remind participants that they may wish to choose a new buddy (other than their partner) to support each other’s progress and action planning during the week.
- 5. Instructions to Leaders:** Remind participants to **keep track of their action plans** daily and to be ready to tell the group about them next week.
- 6. Instructions to Leaders:** Collect name tags.

7. **Instructions to Leaders:** Stay around for 15 minutes or so to answer questions and straighten the room.

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Purpose

- To discuss strategies for dealing with depression
- To introduce the benefits of exercise
- To assist participants in choosing appropriate exercises for a fitness program
- To introduce/reinforce safer sex practices and their importance
- Discuss issues around intimacy and telling others about HIV status
- To introduce techniques for improving communication

Objectives

By the end of this session, group members will be able to:

1. Name 5 symptoms of depression and discuss 3 means of managing mild depression
2. Name at least 5 benefits of exercise
3. Name the 3 types of exercise that make up a complete exercise program
4. Plan an exercise program
5. Identify 2 reasons why safer sex is important
6. Identify 3 barriers to telling others about HIV status
7. Identify a range of communication skills
8. Make an action plan for the coming week

Materials

- Charts:
 - 2: HIV Self-Management Tool Box (**post at all sessions**)
 - 3: Guidelines (**post at all sessions**)
 - 4: Brainstorming (**post at all sessions**)
 - 6: Parts of an Action Plan (**post at all sessions**)
 - 7: Problem-Solving Steps (**post at all sessions**)
 - 8: Symptom Cycle (**post at all sessions**)
 - 15: Three Kinds of Physical Activities and Goals
 - 16: Communication Skills
- Name tags
- Flip chart/felt pens
- Pad of paper, extra pencils
- Tissues

Homework Assignments Given During Session 4

- Start an exercise program or some form of physical activity routine.
- Keep a food diary of what you eat for at least two days next week. We suggest using one day during the week and one day on the weekend because our eating habits are often different on the weekend,
- During the week carry out your action plan and note if there are any challenges and how you overcame them.
- Call your buddy to support each other in your action plans (optional)
- Reading: *Living a Healthy Life with HIV*, Chapters 5, 13, 16, pages 7-9, 47-50, 53, 57-58, 152-157

Reading for Leader's Preparation:

- **Before facilitating this session, look up the HIV disclosure laws in your state/area**
- *Living a Healthy Life*: as homework assignment, above
- Action Plan and Feedback Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of the meeting:

Session Four Agenda

Activity 1: Feedback (20 minutes)

Activity 2: Dealing with Depression (15 minutes)

Activity 3: Physical Activity & Exercise (25 minutes)

BREAK (20 minutes)

Activity 4: Sex, Intimacy & Telling Others (20 minutes)

Activity 5: Communication Skills (25 minutes)

Activity 6: Making an Action Plan (20 minutes)

Activity 7: Closing (5 minutes)

Activity 1

FEEDBACK

20 minutes

Materials

- Feedback Flow Chart, Appendix II

Instructions to Leaders: Encourage participation of all members. Not more than 3-5 minutes should ever be spent on one person. People who discuss their action plans earlier will probably need more time than those who come later. Do not spend all of your time with "yes buts" or other "real" problem people (the general rule is that if someone has said "yes but" three times, you should go on to someone else. Deal with these folks during the break. Please review the **Feedback Flow Chart in Appendix II** to help you make appropriate responses to each participant. This activity works best if one Leader leads the activity and the second Leader follows the feedback with the flow chart and helps as needed.

1. **Say:** Welcome back! The first thing we're going to do today is to report back on the action plans we made last week. Each of us will share our experiences in completing our action plans.

I'll start, and then my partner will report.

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Instructions to Leaders:

- Start with yourself as a model but make it very short.
- Be sure at least one Leader models a plan that has been accomplished.

2. **Say in your own words:** Now we'd like to hear about your action plans. We'll ask for a volunteer than go around the room from that person.

a. First, tell us what your action plan was for the past week.

b. Then tell us how well the action plan was accomplished. You can use words like:

- accomplished
- partially accomplished
- was not able to accomplish
- changed it to another plan

Sometimes plans need to be changed and if this occurred and you substituted something else, this is good self-management.

- c. Finally, if you were not able to accomplish your plan or if you changed your plan, describe the barriers that prevented you from completing your action plan or caused you to change it. If you changed it, tell us how you changed it.

3. Instructions to Leaders: Respond to each participant as follows

In addition to the following instructions, make sure you review the Feedback Flow Chart in Appendix II

<p>If someone reports their confidence level</p> <p style="text-align: center;">↓</p>	<p>If they were successful</p> <p style="text-align: center;">↓</p>	<p>If they met obstacles and adjusted or changed their action plan successfully</p> <p style="text-align: center;">↓</p>	<p>If there were problems and the person was partially successful</p> <p style="text-align: center;">↓</p>	<p>If there were problems and the person was unsuccessful</p> <p style="text-align: center;">↓</p>
<p>tell them that we don't need to report confidence levels from last week</p>	<p>congratulate them</p>	<p>congratulate them for being a good self-manager</p>	<p>comment on the good start they have made (but do not congratulate), and then problem-solve (see problem-solving steps below) with the group, if the person wishes to do so</p>	<p>go through the steps of problem-solving:</p>

Problem-solving Steps with the group:

STEP 1

Ask the person to state the problem they had in completing the plan. Ask them to be specific.



STEP 2

Ask the person if they have any ideas of how to solve the problem or did they try a solution. Stop here if the person has ideas or has already tried a solution.

STEP 3

If the problem is not solved, ask the individual if they would like to hear some suggestions from the group on how to solve the problem. If yes, then continue with the brainstorm in the next steps. If not, move on to the next participant.

STEP 4

Ask the group to **give 4 or 5 possible solutions**. These suggestions should be given without comment or discussion.

STEP 5

Tell the person with the problem that they just listen and get ideas. The group Leaders can also offer suggestions, but *not until* others in the group have participated.

STEP 6

When you have possible solutions (no more than 5) stop the brainstorm, or if you see there are more ideas, tell the group that you'll take one more and then stop the brainstorm. Suggest that they catch the person at break.

Leaders may write these on flip chart or suggest that the person with the problem do so. If you suspect that your group may have people who cannot read, suggest that they remember the ideas instead of writing them down.

STEP 7

Ask original participant if they could use any of the strategies suggested and, if so, which one. Recommend that the participant make a note of the helpful suggestion or remember it.

If no suggestions seem workable, then say you will talk with the person more during the break - and do so.

**REMEMBER, DO NOT SPEND A LOT OF TIME ON ANY ONE PERSON.
AFTER THREE "YES BUTS," GO ON TO THE NEXT PERSON.**

Activity 2

DEALING WITH DEPRESSION

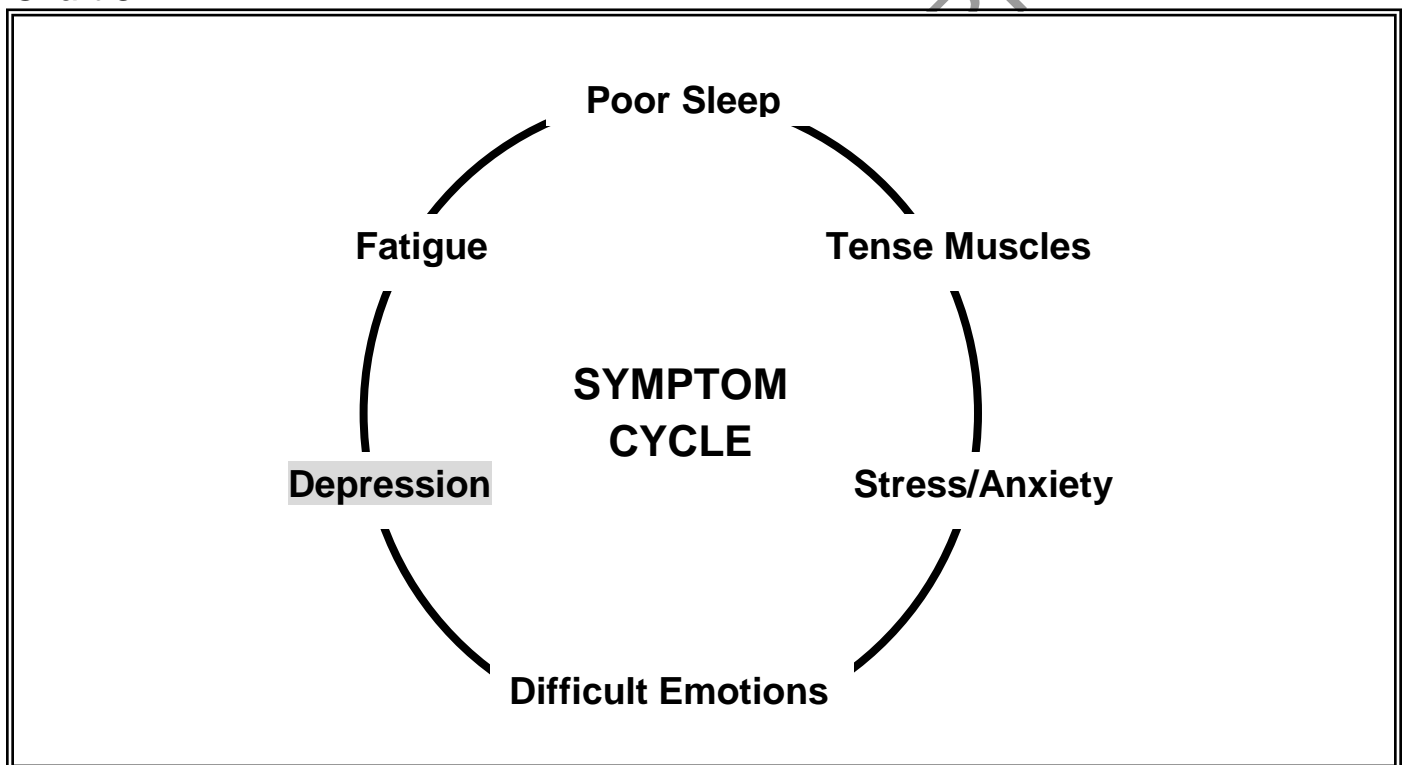
15 minutes

Materials

- Chart 10, “Symptom Cycle”

1. **Say in your own words, pointing to Depression on Chart 8:** As we look at the Symptom Cycle, one of the points that can affect our condition is depression. Unhappy feelings or depression is **just another symptom**, like pain or fatigue. These feelings are part of the normal ups and downs of life, but they can contribute toward the worsening of our other symptoms.

Chart 8



2. **Say in your own words:** We are not talking about depression that stays for weeks or months. We are discussing the unhappy feelings that usually come and go. These we can help with self-management. Severe, long-term depression may need professional help and medication.
3. **Say in your own words:** Before we can do something about these feelings, however, we must be able to recognize that we are depressed. For some people this is not easy so let's discuss how to tell if we're depressed.

4. **Say:** Let's do a brainstorm. The question is:



How do we know if we are depressed?

Instructions to Leaders: Brainstorm the question, writing the responses on the board or flip chart.

When they are finished, read back the list and ask for clarification. Be sure to add any of the following bulleted items **if they are not mentioned**. You do not need to repeat items that appeared as part of the brainstorm.

- a. feeling tired or fatigued (the biggest symptom of depression)
- b. loss of interest in friends or activities
- c. isolation or withdrawal
- d. difficulty or changes in sleep patterns
- e. increased or decreased appetite
- f. loss of interest in personal care or appearance
- g. unintentional weight loss or gain
- h. general feeling of unhappiness, crying
- i. loss of interest in sex or intimacy
- j. suicidal thoughts
- k. frequent accidents
- l. low self-image, loss of self-esteem
- m. frequent arguments or loss of temper (some people express their depression as anger)
- n. feeling confused, lack of concentration
- o. sometimes drinking more than 1 or 2 drinks a day

5. **Say:** Now let's look at ways to deal with it and do another brainstorm:



What are some things we can do to make ourselves feel better when we're depressed, blue, sad, or grouchy?

Instructions to Leaders: After the group has shared, **emphasise** the following methods as being important:

- a. contact with others – calling or going out to lunch with a friend

- b. planning ahead for a special event
- c. getting out of the house everyday
- d. doing something nice for yourself (treat yourself)
- e. exercise (like going for a walk)
- f. doing something to help someone else (volunteer)
- g. cut down or eliminate the use of alcohol or non-prescribed drugs
- h. List the things in your life you are grateful for – practice positive thoughts

If someone mentions **alcohol or not-prescribed drugs** say that these may seem to help depression but in reality, the use of these substances may be a sign of depression and in the long run they make depression worse. Alcohol and many drugs are depressants themselves.

5. **Say in your own words:** It's important to be aware that not all depression can be handled through self-management. Sometimes depression is severe and you may need professional help and medication.

If you feel unhappy for more than a few weeks, or think about harming yourself, it is **VERY** important to talk to your doctor.

Severe, clinical depression is a **biological** illness, and can be treated.

Also, if you are taking medication for depression and are thinking about stopping, talk to your doctor first. Many of these medications should not be stopped suddenly.

7. **Say in your own words:** One very effective technique for dealing with depression and breaking the Symptom Cycle is physical activity and exercise, which we are talking about next.

Activity 3

25 minutes

PHYSICAL ACTIVITY AND EXERCISE

Materials

- Chart 2, “HIV Self-Management Tool Box”
- Chart 15, “Three Kinds of Physical Activities and Goals”

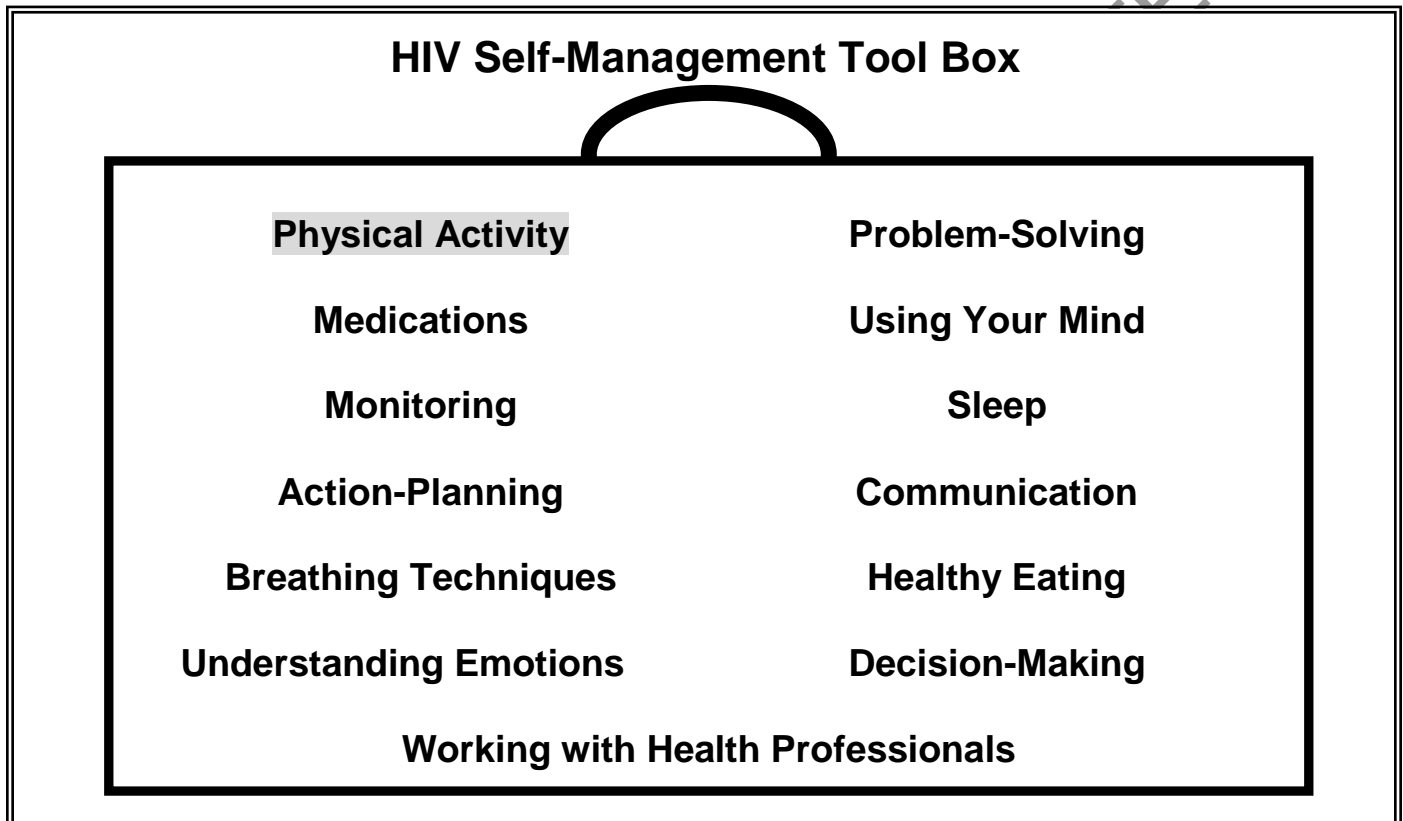
1. **Say in your own words, pointing to “Physical Activity” on Chart 2:** In this

workshop, we will talk about physical activity and exercise for fitness and fun. Being physically active means that you move and are active during the day.

An exercise program means that you set aside times and choose specific exercise to do.

Living with HIV may be challenging, but we can still be fit and enjoy physical activities and exercise. In fact, being physically active and exercising may be two of the best things we can do to help our condition.

Chart 2



2. **Instructions to Leaders:** Invite participants to call out any benefits of physical activity and exercise. You do not need to write these down.



3. **Instructions to Leaders:** Once participants have had the opportunity to give their suggestions, add the following if not mentioned:

- a. Strong cardiovascular system – heart, lungs and blood vessels
- b. Good muscle strength
- c. Good endurance and stamina
- d. Good flexibility

- e. Weight control
 - f. Better sleep
 - g. More energy and less fatigue
 - h. Better balance and coordination which helps prevent falls
 - i. Better function
 - j. Less anxiety and depression
 - k. Less constipation
4. **Say in your own words:** Being more physically active every day, either with an exercise program and/or daily activity, will help you achieve or accomplish many of the things you have mentioned.
5. **Say in your own words:** There are three types of activities or exercises that make up a complete fitness program, and each has a goal to work toward. These are:

Chart 15

Three Kinds of Physical Activities and Goals

- **Flexibility** *(to stretch or loosen muscles and joints. Help to improve balance and coordination and to prepare your body for other exercise or activities such as gardening, shopping, cleaning.)*
Goal: 10 minutes without stopping *(Do these slowly, holding each stretch for a few seconds and breathing to relax as you stretch. These can be done daily and as a warm-up for endurance or aerobic activities.)*
- **Strengthening** *(makes your muscles stronger by working them harder, usually done with weight or against resistance; also help balance and coordination)*
Goal: 8-10 strengthening exercises 2-3 days a week *(Choose 8-10 exercises and start with no more than 5 repetitions of each and slowly increase over 2 weeks to 10 repetitions. It's best not to do strengthening exercise every day – a day between gives your muscles and joints time to adapt and strengthen)*
- **Endurance or Aerobic** *(also called cardiovascular exercise, such as walking, biking, swimming, dancing, which works most of the body)*
Goal: Moderate aerobic activities 30-40 minutes, 3-5 days a week *(the goal is 150 minutes per week total. When exercising at a moderate level, you should be able to talk comfortably while doing the activity.)*

6. **Say in your own words:** Exercise does NOT need to be a workout at the gym! Something as simple as moving your arms and legs during TV commercials is physical activity.
7. **Say in your own words:** There are as many activity or exercise programs as there are people. A program can start with as little as one minute of activity per hour when you are awake, to an hour 5 days a week.

Another example might be 5 minutes of slow walking, followed by a few minutes of brisker walking, and then a few more minutes of slow walking, with flexibility and strengthening exercises before and/or after as part of your warm-up and cool-down periods.

The important thing to remember is to **start where you are now** and gradually increase your activity, working toward these suggested goals.

8. **Say in your own words:** Let's look a little closer at **endurance** exercise. Endurance exercise is also called **cardiovascular or aerobic exercise**. This exercise uses the large muscle groups in rhythmic and repetitive movements. Endurance exercise is any exercise that raises our heart rate, makes us breathe faster, or makes us sweat.
 - a. Examples of endurance exercise are walking, running, dancing, swimming, climbing stairs, and there are many more
 - b. For each person, endurance exercise is different. For some people a 10 minute walk can be an endurance activity, while for someone more fit it may take a 30 minute jog.
9. **Say in your own words:** We should always aim for a moderate intensity work out. We should be working hard enough to get the cardiovascular benefits, but not so hard that we risk injury or great fatigue.
10. **Say in your own words:** Some people with long term health conditions, including HIV, are concerned about starting exercise; they think it might bring on more problems. This, however, is not the case. In fact, it is much more beneficial to do some activity than none at all.
 - a. Once we start, we can learn ways to make sure the activities or exercises we do are safe. So, you ask, how do we know if we've done too much? We keep track of how we are feeling. For example:

- b. If you have more symptoms, such as pain or increased fatigue, 2 hours after you finish your physical activities than before you started you know you have done too much.
- c. This means you do less next time or you work at a less intense level. Also, if you get out of breath or are so tired that you have to stop before 10 minutes of an activity, then you are working too hard and should slow down.

11. **Instruction to Leaders:** Ask participants to think of a physical activity they would like to do and the problems that are preventing them from achieving that goal.

12. **Say:** Now we are going to do a brainstorm:

What are some of the problems preventing you from achieving your physical activity goal?



Instructions to Leaders: Read over the list and ask if anyone needs clarification.

13. **Say in your own words:** Now that we know some of the problems, let's come up with a few solutions to a couple of these.



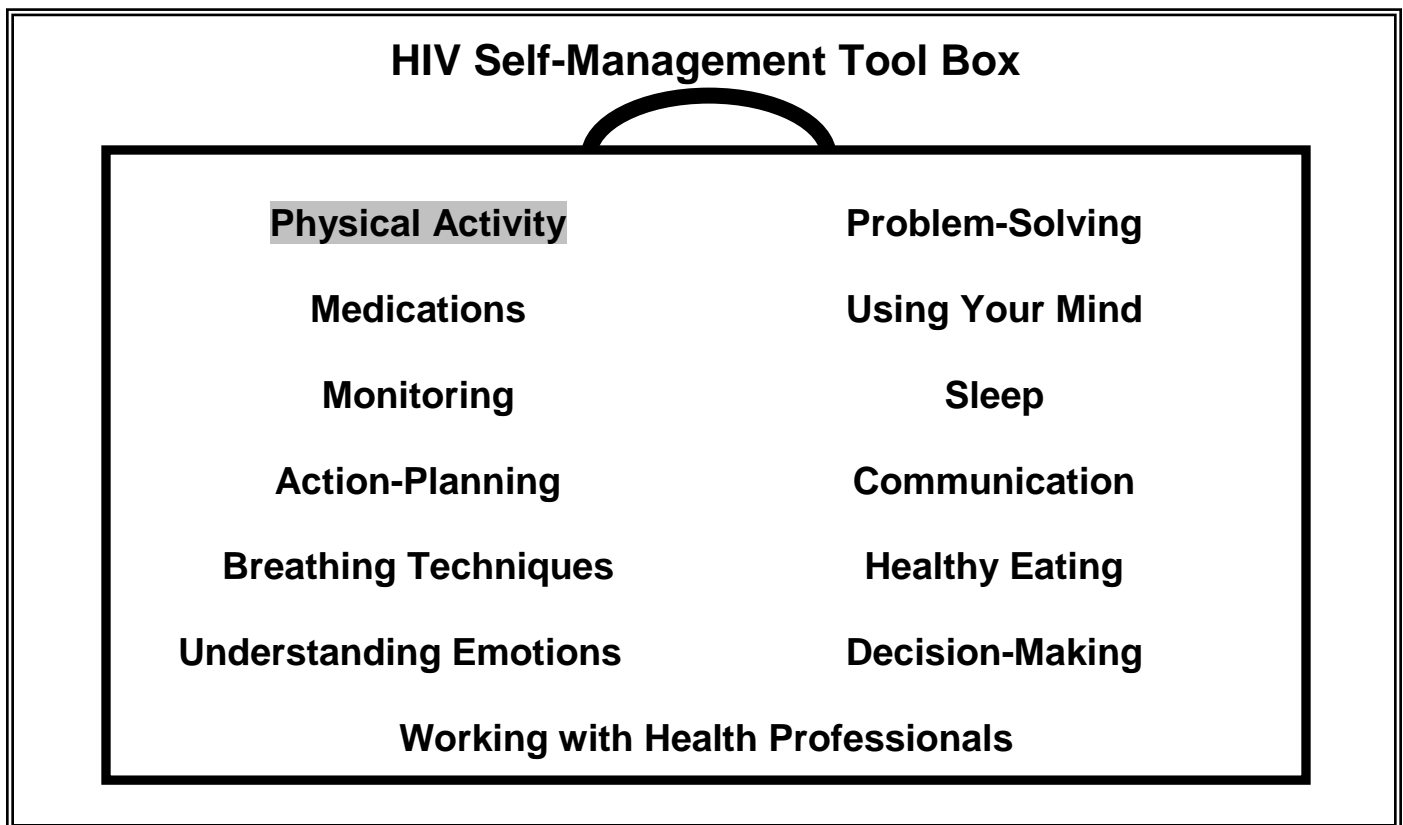
14. **Instruction to Leaders:** Choose one or two of the problems identified above and problem solve.

15. **Instruction to Leaders:** Encourage everyone to choose a goal around physical activity and to start working on the exercises they want to include in their programs. Many people find action planning around physical activity helpful.

16. **Say in your own words, pointing to “Physical Activity” on Chart 2:** Remember, “Physical Activity” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



BREAK

20 minutes

Activity 4

20 minutes

SEX, INTIMACY AND TELLING OTHERS

Materials:

- None

1. **Say in your own words:** Now we're going to discuss the overlapping issues of sex, intimacy, and telling others about our HIV status. We could quite easily run a whole workshop on each of these topics, but the purpose here is to raise the issues, as well as discuss their inter-relationship and the importance of clear communication.
2. **Say in your own words:** Having HIV does not mean that we automatically lose interest in sex and intimacy. In fact, having to deal with all the challenges that

having HIV entails we sometimes need the love and comfort of close, intimate relationships more than ever. However, we sometimes ignore, deny or fear this aspect of our lives. People living with HIV are often concerned about the risk that they might give HIV to someone else.

3. **Say in your own words:** Sex and practicing safer sex is an important aspect of staying healthy, whether we and our partners are HIV positive or not.
 - a. Safer sex means taking precautions to limit the risks to our own health AND that of our partners. We don't want to pass HIV to others. Therefore, knowing our viral load and sticking to our medication plan is important. A low, undetectable viral load means lower risk of transmitting the virus. This is what is meant by U=U, undetectable equals untransmittable.
 - b. Safer sex also includes using a barrier like a condom any time we have sexual contact, but especially with someone whose sexual history we may not know. This prevents the spread of other sexually transmitted diseases (STDs) that are not prevented by taking HIV medications.
 - c. Also, you and your partner may want to consider "Pre-exposure Prophylaxis", or PrEP treatment. This is where an HIV-negative partner takes anti-HIV medications to help prevent contracting the virus. This is not a substitute for barriers to prevent other STDs. PrEP is prescribed and monitored by a doctor and must be taken consistently to be effective.

PrEP is not the same as PEP. PEP is "Post Exposure Prophylaxis". This can be used after exposure has happened, such as a broken condom or accidental needle stick. Like PrEP, an HIV-negative person can take HIV medications to prevent the virus from taking hold. PEP should be started within 72 hours after an exposure and take it as directed by the health care provider, which is usually once or twice daily for a month.
 - d. You may also explore and discuss other strategies with your partner and health care providers.
 - e. You will find more information about these issues in your book and there are additional resources available on the resource table.
4. **Say in your own words:** There are several reasons why it is so important to practice safer sex:

- a. To protect ourselves - even if we are already HIV positive, and even if we have a very low level of virus in our system.
 - It may be that we could be re-infected with a new, more dangerous strain of HIV, or one that is drug resistant.
 - We may be more likely to get other sexually transmitted infections. Some sexually transmitted infections - such as gonorrhoea, herpes, and syphilis – may cause open sores, inflammation or change the tissue of the vagina, anus, throat or urethra which can make it easier for HIV infection to occur.

b. To protect others from getting HIV and sexually transmitted diseases.

5. **Say in your own words:** For many people living with HIV, sex is often linked to other issues we face. For example, there is the issue of telling others and communicating about our HIV status, whether they are sexual partners or anyone else in our lives.

The issue of intimacy, both physical and emotional, can also be complicated by our having HIV.

6. **Say in your own words:** Because sex, love, and intimacy often overlap and because they are such emotional issues for all of us, telling others is a very complex issue.
7. **Say in your own words:** There are different relationships that may affect how or if we share our HIV status.
- a. Telling a family member or close friend is an act of love and intimacy.
 - b. Telling a romantic partner is also an act of love and intimacy, but also includes the issue of sex.
 - c. Telling a casual sex partner can be a loving and intimate thing to share, but many HIV positive people may not be prepared to be that intimate with a casual sex partner.
 - d. Telling people at work, such as a boss and or co-worker, could be an intimate way of sharing our reality, and at the same time being open for their support.

8. **Say in your own words:** Sometimes these differences in life roles can cause confusion. While seeking fulfillment in one of these areas, such as sex, we may be frightened by the intimacy of sharing our HIV status for fear of rejection. As a result, we may become conflicted - and telling someone of our HIV status, whether appropriate or not, may not happen.

9. **Say:** Let's do a brainstorm. The question is:

What are the barriers to telling others?



Instructions to Leaders: Read back the list, ask if any need clarification, and then add any of the following list if they have not been mentioned:

- a. Stigma
 - b. Fear of rejection
 - c. Not wanting to worry people
 - d. People think you're going to die
 - e. Denial
 - f. Need for acceptance
 - g. Depression
 - h. Drugs or alcohol
 - i. People make assumptions about your sexuality and/or illegal drug use
 - j. Fear of losing livelihood
10. **Say in your own words:** Many of these reasons are wrapped up in emotions. Some of the tools in our Tool Box can help you with those. If drugs or alcohol are barriers, we urge you to change these behaviors. You can get some tips in Chapter 5 in your book.
11. **Say in your own words:** Many of the barriers can be helped with better communication skills. Communicating about your health status happens for the sake of all of those involved, the person with HIV and those around us. Think carefully before you tell your status to anyone.

Telling others can open the person sharing this intimate information up for rejection, but it can also open us to support and encouragement. It also allows everyone involved to make informed, responsible decisions concerning their own health and well-being.

12. **Say in your own words, ONLY IF YOU HAVE DISCLOSURE LAWS IN YOUR STATE/AREA:** The issue of telling others, or “disclosure” as it is referred to legally, has been further complicated by the law. Information about the laws affecting HIV disclosure can be found on the HIV.gov website and on the American Civil Liberties Union website.
13. **Say in your own words:** There are no specific rights and wrongs when it comes to discussing your health status with others. Each of us needs to determine what is best for us. Many people, though, avoid telling others because they “just don’t know how to say it”. This is one place that good communication skills can help.
14. **Say your words:** Next, we will look at the dynamics of language and good communication skills that can help us in clear communication.

Activity 5

COMMUNICATION SKILLS

25 minutes

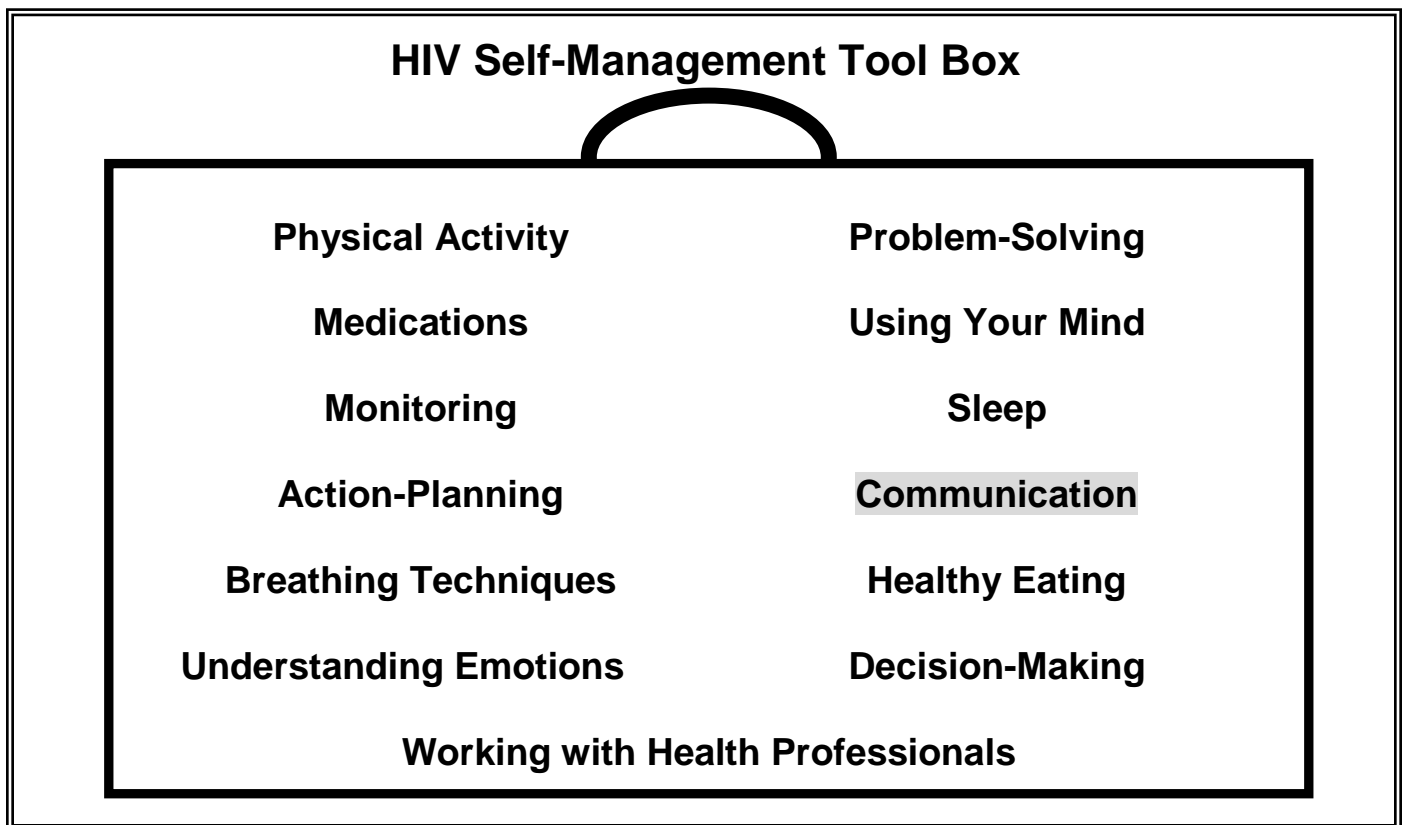
Materials

- Chart 16, “Communication Skills”

1. **Say in your own words, pointing to “Communication” on Chart 2:** We’d probably all agree that good communication is important in all kinds of relationships.

(Chart 2 on the next page)

Chart 2



- a. Knowing how to tell someone that we are HIV positive is very important, but communication is also needed when we are managing any long-term health condition like HIV.
 - b. We must seek information about the condition, keep others informed about our health, and help others to understand how they can help us.
 - c. Good social relationships are also important. Without good communication skills, living with a condition such as HIV can be even more difficult, and problems can arise.
2. **Say in your own words:** One skill we can learn that is particularly good for expressing our feelings and helping with some of the problems that can be caused by poor communication, is the use of "**I messages**" instead of "**You messages**".
- a. By "I", we mean ourselves, not our "eyes". [Leader should distinguish these two by pointing to themselves, and then to their eyes.]
 - b. The "I message" allows us to express concerns or feelings, such as anger or frustration, without blowing up, seeming to blame others, or causing defensiveness in others.

- c. "You messages" tend to block further communications.
 - d. In addition, "I messages" are a good way of constructively expressing anger and fear.
3. **Say:** Let's give you an example of both "I" and "You" messages. Listen carefully to the differences in this dialogue and note how each one makes you feel.
4. **Instruction to Leaders:** Role-play an "**I message**" and "**You message**" version of a verbal exchange between a person with a HIV and their partner using **either** script below.

(Script #1 on the next page)

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SCRIPT #1 – Sex and Intimacy

"You Message" Example:

Partner 1: You're never interested in sex anymore. I wish you would just try to show some interest.

Partner 2: *You seem to have nothing else on your mind but sex. I have so many other things to worry about right now.... juggling my meds, exercising, eating right.*

Partner 1: But what about me? Why don't you make me one of your priorities? You're being very self-centred.

Partner 2: *ME, self-centred! You're the one being self-centred!!*

Partner 1: Well, I can see once again talking about this is getting us nowhere. It just makes it worse!

"I Message" Example:

Partner 1: I really miss having sex with you. It's been a while, hasn't it?

Partner 2: *Yes, it has. I just feel so overwhelmed with trying to adjust to the medication schedules and trying to focus on staying healthy, that I don't have the energy I used to.*

Partner 1: I never really thought about that. Still, I miss feeling close and intimate with you. Having sex helps me feel closer to you.

Partner 2: *I really miss that too, but I just don't have the energy. I feel tired most of the time*

Partner 1: Maybe we could just spend time alone holding each other and talking. This will help me feel close to you again.

Partner 2: *That would feel great. I miss cuddling with you, but I didn't want to make you think I was initiating having sex. Talking about this is great.*

Partner 1: That sounds great to me. Maybe we can come up with some ideas of how I can help you with some of these things.

(Script #2 on the next page)

“You Message” Example

Partner 1: Hurry up! You’re always late.

Partner 2: *Instead of picking on me, why can’t you just slow down!*

Partner 1: I just think if you were not so lazy, we wouldn’t always be going through this.

Partner 2: *How dare you call me lazy! You try dealing with what I have to.*

“I Message” Example

Partner 1: It’s time to go and I’m concerned our friends will leave without us. Are you almost ready?

Partner 2: I’m running a little late because I’m extremely tired from my new medications. I’d be ready sooner if you could help me out.

Partner 1: I forgot you were on new medications. How can I help?

Partner 2: Can you call and tell our friends we’re running late?

Partner 1: That’s a good idea. Maybe we can talk later, too. Sometimes I get scared by how much more slowly you move when you’re tired like this, and I don’t know how to help. Maybe if I understood more, we could figure out ways to make things easier for both of us.

Partner 2: I’m worried, too. I get scared I won’t be able to do things, or that you’ll leave me because of how much is involved in dealing with HIV. I think talking more would be good.

5. **Say:** What differences did you notice between the two dialogues?
6. **After they have discussed this, say in your own words:** The use of the "I" message allowed their communication to reach the point where they were able to express the real problem without blaming each other.
- "I messages" made it possible to find a **solution** to the problem, instead of leaving each other with hurt feelings.
 - The "You messages" tended to be more aggressive and hostile putting the receiver on the defensive. They blocked further communications and the opportunity to find a solution to the problem.



7. **Say in your own words:** Sometimes using “I” messages can be difficult, especially at first. If this is the case, try a variation in which you state the problem and then tell how it makes you feel. For example,

- When you come home late, I worry.
- When you won’t hold me, I feel ugly or unwanted.

These may seem like you messages, but really do differ because they state a fact or situation and then what you feel about it. They are not aggressive or hostile and allow one to express feelings.

8. **Say in your own words:** Sometimes communication problems are harder to identify. It may not be what we say or how we say, but rather what is **not** said that is a problem. Listen carefully to the following conversation between two friends and decide if there is a problem, and if so, what is it.

Example #1

Friend 1: Hello *(Leader’s name)*. I’m so sorry, but I can’t go out to lunch with you today. I’m just too tired.

Friend 2: *That’s okay. I know that your condition is often unpredictable. Is there anything I can do to help?*

Friend 1: No. I just have to live with it. Nothing can be done.

Friend 2: *Oh, okay. Then I’ll say bye for now. I’ll talk to you soon.*

Friend 1: OK. Bye

9. **Ask: Is there a problem here?**



Instructions to Leaders: If the participants do not identify that Friend 1 cut off the conversation early by not accepting help, **do not point this out yet.** Rather, have them listen to another version of the same conversation to see if they can notice the difference.

If they do identify that Friend 1 created a problem by cutting off communication, tell them that this is correct. Then have them listen to the second version of the conversation to see how this might change.

Example #2

Friend 1: Hello (Leader's name). I'm so sorry, but I can't go out to lunch with you today. I'm just too tired.

Friend 2: *That's okay. I know that your condition is often unpredictable. Is there anything I can do to help?*

Friend 1: I really appreciate your understanding. Any chance of you picking up some take-out and coming here for lunch instead. I have to eat and I'd still like you to visit for a while.

Friend 2: *That's a good idea. I'd love to come over. What type of food would you like?*

Friend 1: Chinese food or chicken would be good. How about you?

Friend 2: *Chinese sounds good. See you around noon.*

10. **Instructions to Leaders:** Ask participants what the difference was in the second dialogue. Be sure to point out that very often family and friends want to offer help, and it is our job to tell them how they can help or what it is we need. We cannot expect them to "just know."



11. After they briefly discuss this, **say in your own words:**

- a. Sometimes a breakdown in communication occurs when we don't say what we want or need, especially when it involves asking for help.
- b. In the first example, the person with the health problem didn't let her friend know what she really wanted. Instead, she gave in to her tiredness and gave up, and by telling her friend nothing could be done, shut down any further communication.
- c. In the second example, she opened up and shared what she wanted and the end result was better for both people.

12. **Say in your own words:** All of us have experienced communication problems at one time or another. Sometimes we are not clear about our wants and needs.

Other times the people around us don't understand us, and therefore don't know how to approach or help us. It may appear that they don't care, or that their attempts to help are inappropriate.

Sometimes, the subject we need to talk about is difficult to get started. If we can learn to communicate more effectively, then perhaps we can avoid some of these problems.

13. **Say, pointing at Chart 16:** Here are some suggestions to help us improve our communication skills:

Chart 16

Communication Skills

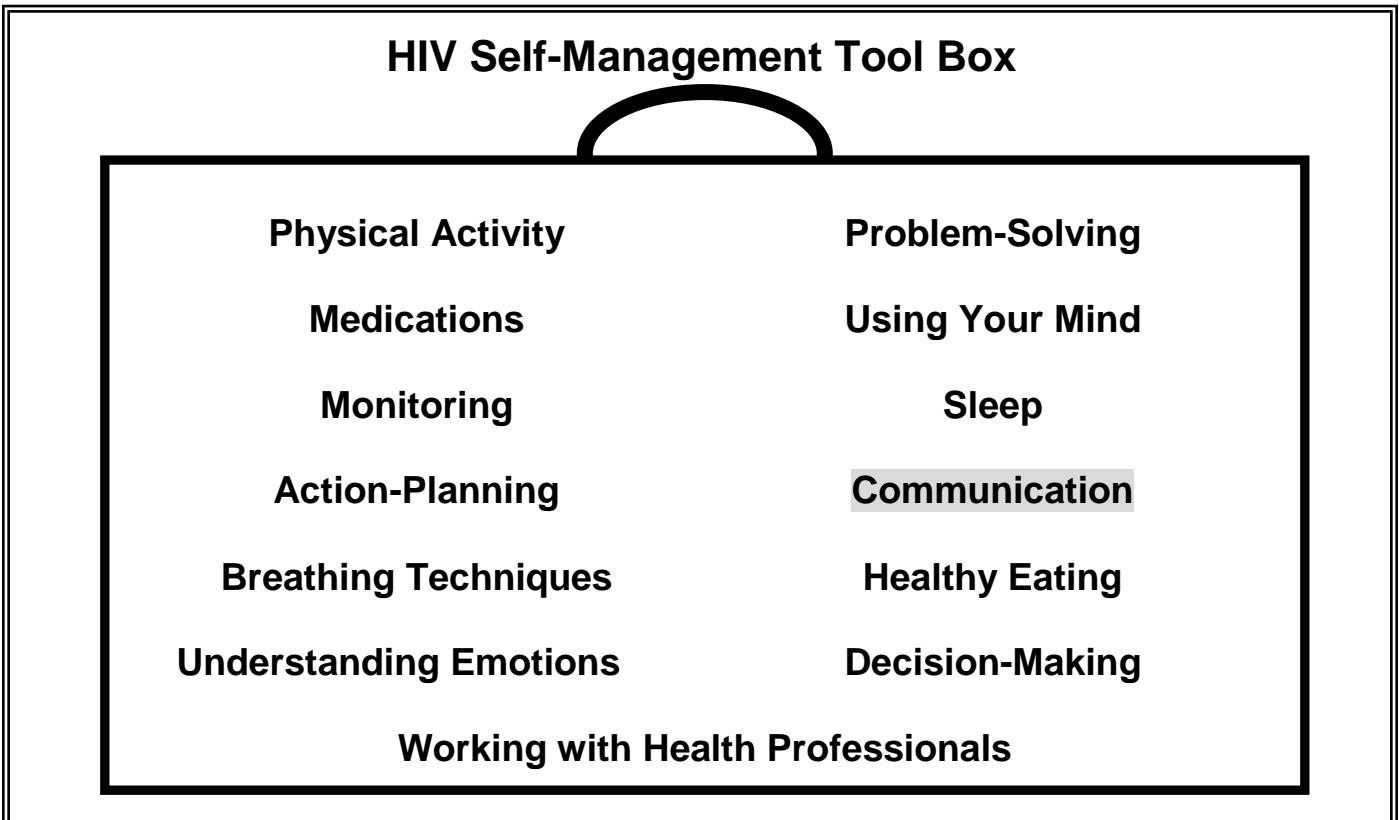
1. **Identify** (*what is really bothering you and how you feel about it. This may not be easy, and may take some honest thinking to achieve*)
2. **Express your feelings** (*constructively, in one of two ways*)
 - **Use direct "I" messages.** (*for example: "I feel I'm not being heard" is better than "You never listen to me."*)

(When we first start using I messages, we need to watch out for hidden "you messages" that have "I feel" stuck in front of it, such as I feel frustrated when you act like a fool.)

(These messages are also good to use to express positive emotions and feelings to others, which help improve our relationships.)
 - **Use "When this happens...I feel..."** (*For example: "When I'm not able to talk about my plans for future health care, I feel frightened that my wishes will not be carried out." For some, this way of expressing feelings might be easier than the more direct form.*)
3. **Listen attentively** (*sometimes we are so anxious to respond that we don't really hear what others are saying to us. Try waiting a few seconds after the other person has finished before responding. Good listening is the other part of good communication.*)
4. **Clarify** (*repeat what you think you heard using your own words, then ask for clarification. For example, "Something about taking the new meds bothers you. Can you tell me what it is?"*)

14. **Say in your own words:** These can be useful techniques to use with partners, friends, colleagues, or health care professionals.
15. **Say in your own words, pointing to “Communication” on Chart 2:** Remember, “Communication” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

Chart 2



Activity 6 MAKING AN ACTION PLAN

20 minutes

Materials

- Chart 6, “Parts of an Action Plan”
- Action Plan Flow Chart, Appendix II

1. **Say in your own words:** Now it’s time to make our action plans for this week.

Remember that action plans allow us to achieve what we want or decide to do by breaking down the activity into smaller, more “doable” steps or tasks.

2. **Say in your own words, pointing at Chart 6:** Let's hear everyone's action plan, looking at parts 4 and 5 on our chart:

Chart 6

Parts of an Action Plan

1. **Something YOU want or decide to do**
2. **Achievable** (*something you can expect to be able to do this week*)
3. **Action-specific** (*for example, gaining or losing weight is not an action or behavior, but adding or avoiding snacks-between meals is; gaining or losing weight is the RESULT of actions*)
4. **Answer the questions:**
 - What?** (*the specific action*)
 - How much?** (*it's time, distance, amount*)
 - When?** (*time of day or days of the week*)
 - How often?** (*number of times in the week; avoid "every day"*)
5. **Confidence level of 7 or more** (*On a scale of 0=not at all sure to 10=totally sure*)

3. **Say in your own words:** We'll start with our own action plans for the week.

4. **Instructions to Leaders:** One Leader should go through each step on Chart 6 (pointing at each step while standing next to it), using their own action plan. Start by saying what you are trying to accomplish such as exercise more.

IMPORTANT
MODELING
MOMENT



PREPARE BEFORE SESSION: Leaders should prepare action plans in advance with each other, remembering that the Leader's action plans will be **MODELS** for the rest of the participants. This means that your action plan should be something you really want to do and will complete.

If possible, at least one Leader's Action plan should be around behaviors taught in the workshop. Also, it should appear reasonable to the participants. For example, even if you normally walk 5 miles a day, tailor your action plan so it is not too intimidating to the group. Make a plan for a half a mile a day instead.

Leaders should make action plans around different things, for example, one might be about exercise, and the other about relaxation. Be careful to make the action plan for 3-4 times a week, rather than 5-7, and report a confidence level of 7-9.

5. **Say in your own words:** Now my partner will share their plan.

IMPORTANT
MODELING
MOMENT



Instructions to Leaders: The second Leader reports their action plan, answering each of the questions on Chart 6 as the first Leader points to them.

6. **Instructions to Leaders:** Emphasize that the action plans must be:

- something you *want or decide to do*
- *achievable*, that is you can expect to achieve it in the next week

7. **Say in your own words:** Please tell us your action plan for this week, and how sure you are that you will complete the plan, 0 being not at all sure and 10 being totally sure.

8. **Instructions to Leaders:** Ask for a volunteer to start reporting actions plans and then go around the room from that person (do not ask for a second volunteer).

Point to each step (what, how much, when, how often, confidence level) on Chart 6 as each participant reports their plan. See Appendix 2, Making an Action Plan Flow Chart

9. **Instructions to Leaders:** If confidence level is less than 7, ask the participant what the problem might be and if they encounter the problem, what would they do.



Ask the participant if they would like suggestions from the group.

If they say yes, have the group offer 4-5 suggestions and the original participant should not comment.

After all the comments ask the participant “if you have (name the problem) what will you do?” Participants can change the plan if they wish.

Ask the participant to state the new or amended action plan, starting with “I will”.

10. **Instructions to Leaders:** If someone is having trouble writing a clear action plan (i.e., specific activity, times per day, days per week), go through the same steps as above, **asking other group members for suggestions** *before* you help.

Do not spend more than 3 minutes with any one person. If someone is having problems, work with them individually *afterwards*.

If someone does not want to make an action plan say that is OK and that you will come back to them later—then go back to the person after everyone has made their plan. If they still do not want to make a plan that is OK.

NOTE TO LEADERS: See **Making an Action Plan Flow Chart in Appendix II** for details on how to help someone make an action plan.

Activity 7 CLOSING

5 minutes

1. **Instructions to Leaders:** Encourage participants to start an exercise program or some form of physical activity routine.

2. **Say in your own words:** Next week we will be looking at healthy eating and we would therefore like you to keep a food diary of what you eat for at least two days next week.

We suggest using one day during the week and one day on the weekend because our eating habits are often different on the weekend.

3. **Say in your own words:** Next week we will also be discussing **healthy eating**, getting a **good night's sleep**, **planning for the future** and **positive thinking**.

4. **Instructions to Leaders:** Encourage participants to choose a new buddy to support each other's progress and action plans during the week.

5. **Instructions to Leaders:** Remind participants to **keep track of their action plans** daily and to be ready to tell the group about them next week.

6. **Instructions to Leaders:** Collect name tags.

7. **Instructions to Leaders:** Stay around for 15 minutes or so to answer questions and straighten the room.

Purpose

- To raise awareness of current diet and importance of healthy eating.
- To give an overview of good nutrition
- To identify some ways to change eating practices
- To discuss the role of good quality sleep and the ways to get it
- To introduce planning for long-term future and legal issues
- To introduce positive thinking
- To allow participants to practice problem-solving

Objectives

By the end of this session, group members will be able to:

1. Define healthy eating and what constitutes a balanced healthy diet
2. Discuss 3 key nutrients and how to use these in meal planning
3. Name at least 3 ways to improve the quality of their sleep
4. The name the types of advance directives
5. Demonstrate changing negative thinking to positive thinking
6. Make an action plan for the coming week

Materials

- Charts:
 - 2: HIV Self-Management Tool Box (**post at all sessions**)
 - 3: Guidelines (**post at all sessions**)
 - 4: Brainstorming (**post at all sessions**)
 - 6: Parts of an Action Plan (**post at all sessions**)
 - 7: Problem-Solving Steps (**post at all sessions**)
 - 8: Symptom Cycle (**post at all sessions**)
 - 17: The Plate Method
 - 18: Healthy Eating Guidelines
 - 19: Advance Directives
 - 20: Steps Toward Positive Thinking
- Name tags
- Flip chart/felt pens
- *Living a Healthy Life with HIV*
- Pad of paper, extra pencils
- Tissues

Homework Assignments Given During Session 5

- Prepare a letter or e-mail to your health care provider about your experience in the workshop. If you are unhappy with the workshop, please send the letter or email to the Self-Management Resource Center, PO Box 219, Aptos CA 95001 USA.
- During the week carry out your action plan and note if there are any challenges and how you overcame them.
- Call your buddy to support each other in your action plans (optional)
- Reading: *Living a Healthy Life*, Chapter 14, pages 148-152, 178-180, 276-283, 315-322

Reading for Leader's' Preparation

- *Living a Healthy Life*: as homework assignment, above
- Making an Action Plan Flow Chart, Appendix II
- Feedback Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of the workshop:

Session Five Agenda

Activity 1: Feedback (20 minutes)

Activity 2: Healthy Eating (20 minutes)

Activity 3: Getting a Good Night's Sleep (10 minutes)

BREAK (20 minutes)

Activity 4: Future Planning and Legal Issues (20 minutes)

Activity 5: Positive Thinking (25 minutes)

Activity 6: Making an Action Plan (20 minutes)

Activity 7: Closing (5 minutes)

Activity 1

FEEDBACK

20 minutes

Materials

- Feedback Flow Chart, Appendix II

Instructions to Leaders: Encourage participation of all members. Not more than 3-5 minutes should ever be spent on one person. People who discuss their action plans earlier will probably need more time than those who come later. Do not spend all of your time with "yes buts" or other "real" problem people (the general rule is that if someone has said "yes but" three times, you should go on to someone else. Deal with these folks during the break. Please review the **Feedback Flow Chart in Appendix II** to help you make appropriate responses to each participant.

1. **Say in your own words:** Welcome back! Let me draw your attention to the activities we are going to cover today...the first thing we're going to do today is to report back on the action plans we made last week. Each of us will share our experiences in completing our action plans. I'll start and then my partner will report.

Instructions to Leaders: Start with yourself as a model but make it very short. Be sure one Leader models a plan that has been accomplished, and the other where a modification was made and then completed.

IMPORTANT
MODELING
MOMENT



2. **Say in your own words:** Now we'd like to hear about your action plans.
 - a. First, tell us what your action plan was for the past week.
 - b. Then tell us how well the action plan was accomplished. You can use words like:
 - accomplished
 - partially accomplished
 - was not able to accomplish
 - changed it to another plan

Sometimes plans need to be changed and if this occurred and you substituted something else, this is good self-management.

- c. Finally, if you were not able to accomplish your plan or if you changed your plan, describe the barriers that prevented you from completing your action plan or caused you to change it. If you changed it, tell us how you changed it.

3. Instructions to Leaders: Respond to each participant as follows

In addition to the following instructions, make sure you review the Feedback Flow Chart in Appendices

If someone reports their confidence level ↓	If they were successful ↓	If they met obstacles and adjusted or changed their action plan successfully ↓	If there were problems and the person was partially successful ↓	If there were problems and the person was unsuccessful ↓
tell them that we don't need to report confidence levels from last week	congratulate them	congratulate them for being a good self-manager	comment on the good start they have made (but do not congratulate), and then problem-solve (see problem-solving steps below) with the group, if the person wishes to do so	go through the steps of problem-solving:

Problem-solving Steps with the group:

STEP 1

Ask the person to state the problem they had in completing the plan. Ask them to be specific



STEP 2

Ask the person if they have any ideas of how to solve the problem or did they try a solution. Stop here if the person has ideas or has already tried a solution.

STEP 3

If the problem is not solved, ask the individual if they would like to hear some suggestions from the group on how to solve the problem. If yes, then continue with the brainstorm in the next steps. If not, move on to the next participant.

STEP 4

Ask the group to give 4 or 5 possible solutions. These suggestions should be given without comment or discussion. Refer to Chart 4 (Brainstorming) to remind people.

STEP 5

Tell the person with the problem that they just listen and get ideas. The group Leaders can also offer suggestions, but *not until* others in the group have participated.

STEP 6

When you have 5 possible solutions stop the brainstorm, or if you see there are more ideas, tell the group that you'll take one more and then stop the brainstorm. Suggest that they catch the person at break.

Leaders may write these on the flip chart or suggest that the person with the problem do so. If you suspect that your group may have people who cannot read, suggest that they remember the ideas instead of writing them down.

STEP 7

Ask the original participant if they could use any of the strategies suggested and, if so, which one. Recommend that participant make a note of the helpful suggestion or remember it.

If no suggestions seem workable, then say you will talk with the person more during the break - and do so.

REMEMBER, DO NOT SPEND A LOT OF TIME ON ANY ONE PERSON. AFTER THREE "YES BUTS," GO ON TO THE NEXT PERSON.

Activity 2

Healthy Eating

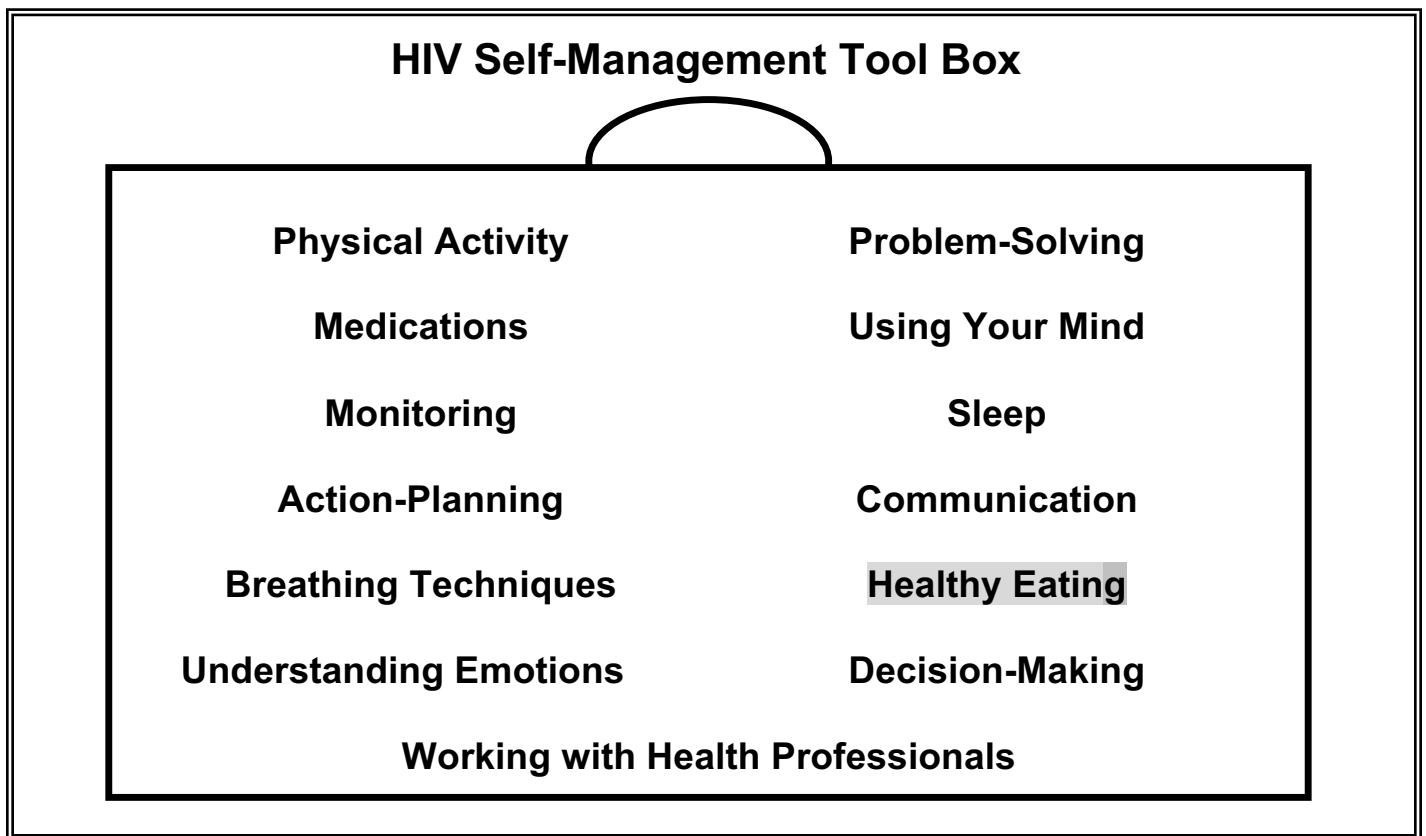
20 minutes

Materials

- Chart 2, “Self-Management Tool Box”
- Chart 17, “The Plate Method”
- Chart 18, “Healthy Eating Guidelines”

1. **Say in your own words:** Eating well is important for everyone, particularly if you are living with HIV. Generally, people living with HIV follow the same healthy eating advice as everyone else.
 - a. A balanced healthy eating plan gives you more energy and helps your body’s immune system to fight off illness and can help prevent other health problems.
 - b. Obesity is becoming more common in people with HIV. It can cause several other health problems, such as type 2 diabetes, high blood pressure, heart disease, and an increased risk of developing certain cancers.
 - c. Weighing too little can weaken your immune system and possibly lead to bone problems and lack of energy.
 - d. We will discuss weight management in more detail next week.
2. **Instructions to Leaders – Give this information ONLY if lipodystrophy comes up:** The anti-HIV drugs commonly used today are much less likely to cause the body-shape changes, called lipodystrophy, that some older drugs did. So, if you notice an increase in your weight and accumulation of soft fat around your belly or in other part of your body, this is likely to be routine fat gain associated with eating too much and not doing enough exercise. There is more information about lipodystrophy in your book, *Living a Healthy Life with HIV*.
3. **Say in your own words, using Chart 2, pointing to Healthy Eating:** Healthy eating is one of the tools in our Self-Management Tool Box, but changing our eating habits is not easy. Before we can change, we need to know what part of our eating habits we would like to change.

(Chart 2 on the next page)



4. **Say in your own words:** Last week we kept track of what we ate. We'd like a few of you to volunteer to tell us what you discovered.

I'll start: I learned I don't eat enough vegetables. *(or some other appropriate example)*

Instructions to Leaders: Have one or two people **briefly** tell what they learned. You do not need to write this down. Do not do the whole group; you do not have time. Reports should be short and there should not be discussion.



5. **Say in your own words:** We can learn a lot from our food diaries.

The best way to know what changes you want to make is to really know what you are eating now. A food diary is an excellent way of finding this out. Also, you might find it helpful to repeat this exercise once a month or so.

6. **Say:** Can some of you call out **some of the benefits of healthy eating?**

Instructions to Leaders: Get 4 or 5 ideas. Do not write them down.



7. **Instructions to Leaders:** After the call out, add items not mentioned from the following list. Do not write them down.

- a. Be less tired and have more energy
- b. Help control and/or maintain weight
- c. Improve endurance and stamina
- d. Maintain muscle strength
- e. Improve or maintain the body's ability to fight infection
- f. Improve comfort and well-being
- g. Prevent deficiency of vitamins and important nutrients
- h. Look good and feel good about ourselves
- i. Absorb medications and minimize side effects
- j. Help control blood sugar, fat and cholesterol
- k. Keep bones and kidneys functioning properly
- l. Maintain the chemical balance in our bodies
- m. Help prevent side effects from medications
- n. Help control blood pressure
- o. Possibly prevent some forms of cancer

8. **Say in your own words:** Healthy eating means:

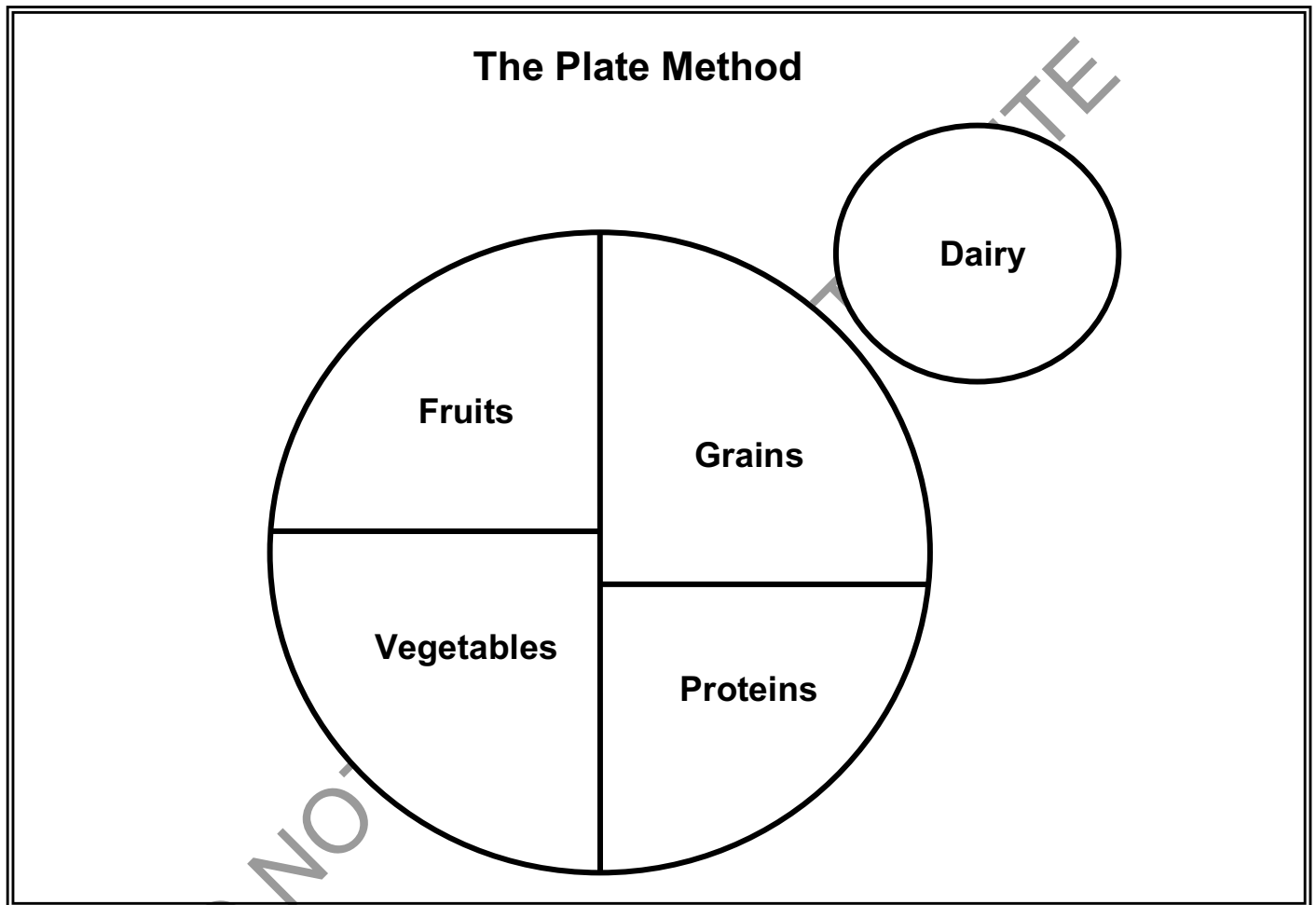
- a. Eating a variety of foods
- b. Eating meals and snacks on a regular schedule
- c. Watching our portion size - Often our portion sizes are much bigger than we realize. You can find specific information about portion sizes in your book.
- d. Eating breakfast - It gives us a kick start for the day and can help us eat less during the day. What you eat isn't important as long as it is healthy.

9. **Say in your own words:** Healthy eating does not mean you have to give up the foods you like or that you have to buy "special" foods. Rather, it means learning to make healthier food choices.

Therefore, in this workshop we don't talk about diets, but discuss guidelines to help us begin to make small, gradual changes in the way we eat. This is the way to change habits.

10. **Say in your own words, pointing at Chart 17:** One way to eat better is to use the Plate Method to plan your meals. This was developed by the U.S. Department of Agriculture. The plate should be about 9 inches across.

Chart 17



The plate is divided in half. Then, each half is divided in two, but notice that the four sections are not of equal size. That is because at each meal, your plate should be:

[Instructions to Leaders: Point to plate as you explain the following]

- On the left side of the plate, a little more vegetables than fruit
- On the grain and proteins side, a little more grains than proteins

- Grains should be from whole grains, like whole grain bread, tortillas and pasta, grits, brown rice, and so on.
- Proteins should be from either lean animal or plant sources
- To this you can add a glass of low-fat milk or some other dairy product like yogurt.

11. **Say in your own words, pointing at chart 18:** Here are some guidelines when making our food choices.

Chart 18

Healthy Eating Guidelines

- 1. Work toward 5 portions of fruit and/or vegetables a day**
 (*● These are a good source of fiber, vitamins and minerals*)
 - *They help to avoid constipation*
 - *They have no cholesterol and are a healthy source of carbohydrates*
 - *Depending on how they are prepared, they have little or no fat*
 - *If 5 portions seem like a lot, then work at gradually adding a portion or two each day. This might make a good action plan.)*
- 2. Choose foods lower in fat**
 (*● Choose leaner cuts of meat, eat more fish.*)
 - *Eat combinations of plant proteins, like rice with beans.*
 - *Use unsaturated fat. These are liquid at room temperature, like olive oil.*
 - *Avoid saturated fats that are solid at room temperature, like butter.*
 - *As you read labels, it is best to eat foods with no more than 5 grams of fat per portion.)*
- 3. Limit foods that can raise cholesterol.** (*This is important for maintaining good blood pressure and for preventing heart attacks and stroke. Two things determine our cholesterol; heredity and diet. We cannot change heredity, but we can change what we eat.*)
 - *Eat less meat and dairy products as cholesterol is only found in animal products.*
 - *Avoid or limit saturated and trans fats because they cause our bodies to make cholesterol. Trans fats are solid at room temperature, but do not come from animals.)*

(Chart 18 continued on the next page)

(Chart 18, continued)

4. Watch carbohydrates

(Most of the time, choose carbohydrates that come from healthier sources such as breads, grains, pastas, vegetables and fruits, rather than sweets like, pastries, candy, sugars, jellies, etc. which also tend to be higher in fat.)

5. Reduce the amount of salt or sodium *(these can increase blood pressure and heart disease. Sodium is often hidden so be sure to read labels. Reduce the amount of salt added to food or do not add at all.)*

6. Maintain a healthy weight

7. Use safe food preparation methods *(Safe food preparation such as sanitizing cutting boards, keeping sponges and dish towels clean, and making sure our refrigerator is set to a safe temperature is important with anyone with HIV. If our immune systems are weakened, we can get sick from contaminated food. For more information about food preparation and HIV-specific information about healthy eating, look in Chapter 15 in your Living a Healthy Life book.)*

12. **Say in your own words:** We acknowledged earlier that changing eating habits can be a challenge, so we want to spend a short time looking at some of the barriers to healthy eating. Can some of you call out **what are some barriers to healthy eating?**



Instructions to Leaders: Take 4 or 5 examples. Write them on the board or flip chart.

13. **Say in your own words:** Now that we know some of the problems, let's problem-solve a couple of these.

14. **Instructions to Leaders:** Have the group choose one or two of the problems identified and problem-solve.

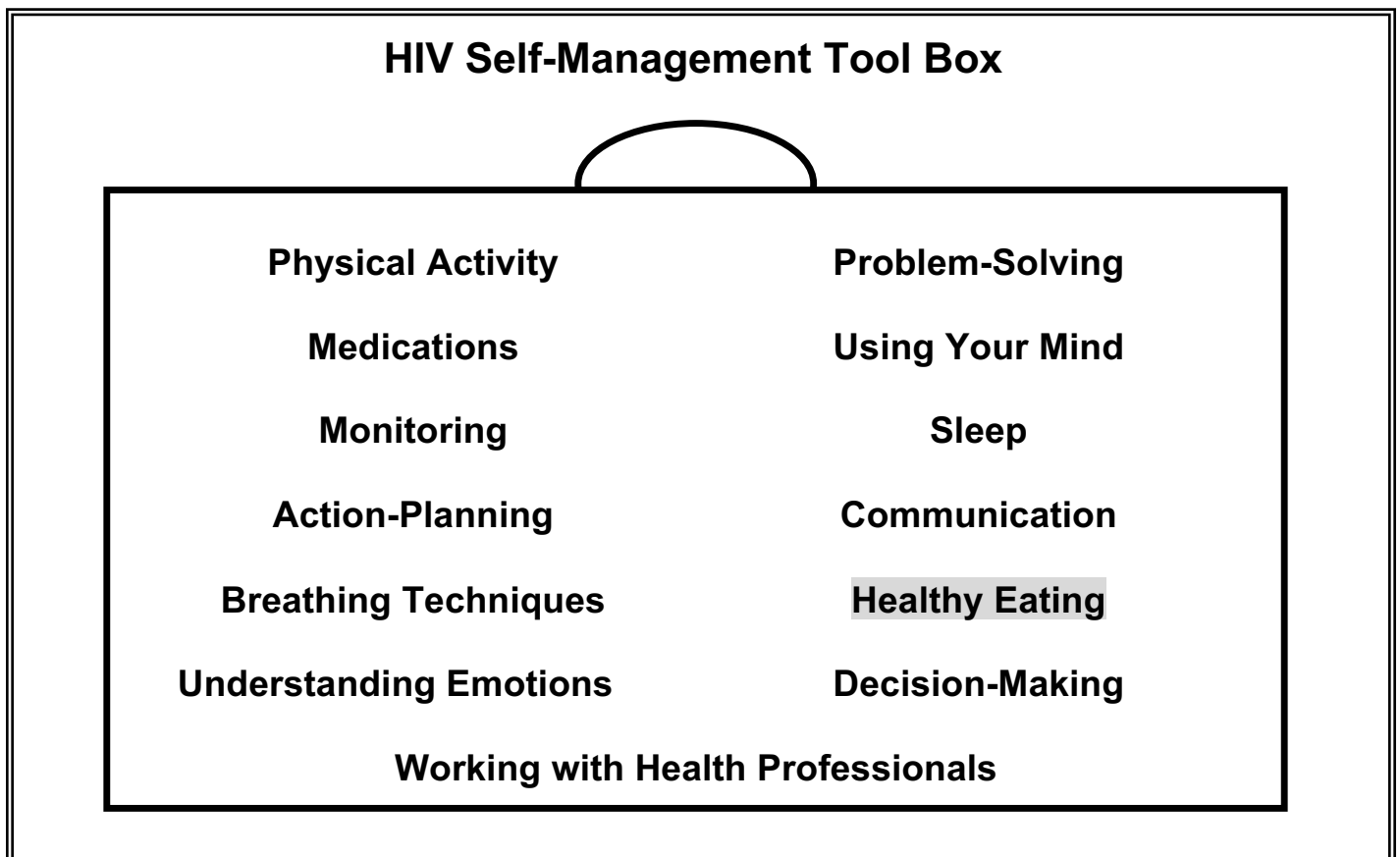


15. **Say in your own words:** If you would like to make a change to what you eat perhaps this could be incorporated into your **action plan** for this week.

16. **Say in your own words, pointing to “Healthy Eating” on Chart 2:** Remember, “Healthy Eating” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



17. **Say in your own words:** Now we'll talk about ways to help with something that is all too common problem these days, sleep.

Activity 3

10 minutes

GETTING A GOOD NIGHT'S SLEEP

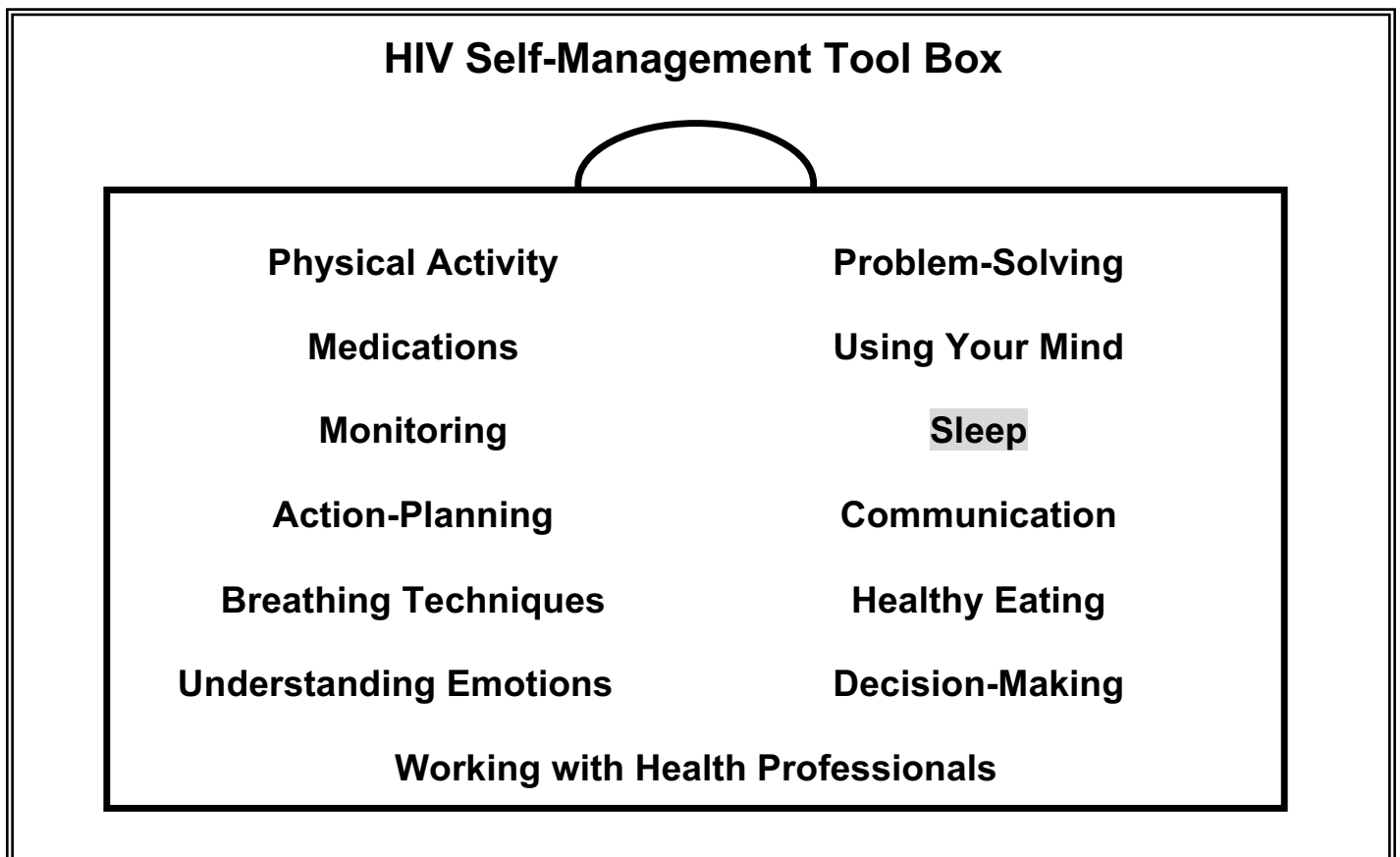
Materials

- Chart 2, "HIV Self-Management Tool Box"

1. **Say in your own words, pointing at "Sleep" on Chart 2:** Getting quality sleep on a regular basis can also help manage our symptoms.

(Chart 2 on the next page)

Chart 2



2. **Say in your own words:** When we sleep, our bodies secrete hormones that help the body heal by repairing the wear and tear that has naturally occurred in our tissues during the day.

Getting quality sleep is especially important for people with health conditions, including HIV, because it helps the body and mind to recover. Research suggests that developing good sleep patterns and managing sleep problems can help improve many physical and mental health conditions.

3. **Say in your own words:** Although the amount of sleep is different for all, getting good sleep is sometimes easier said than done. Having difficulty sleeping is not an uncommon complaint. We may have trouble getting to sleep, we may wake up often, or we may not be able to go back to sleep once we have awakened.

4. **Say:** Let's brainstorm: The question we are going to brainstorm is:

What are some ways to get a good night's sleep?

Instructions to Leaders: When they are finished, read over the list

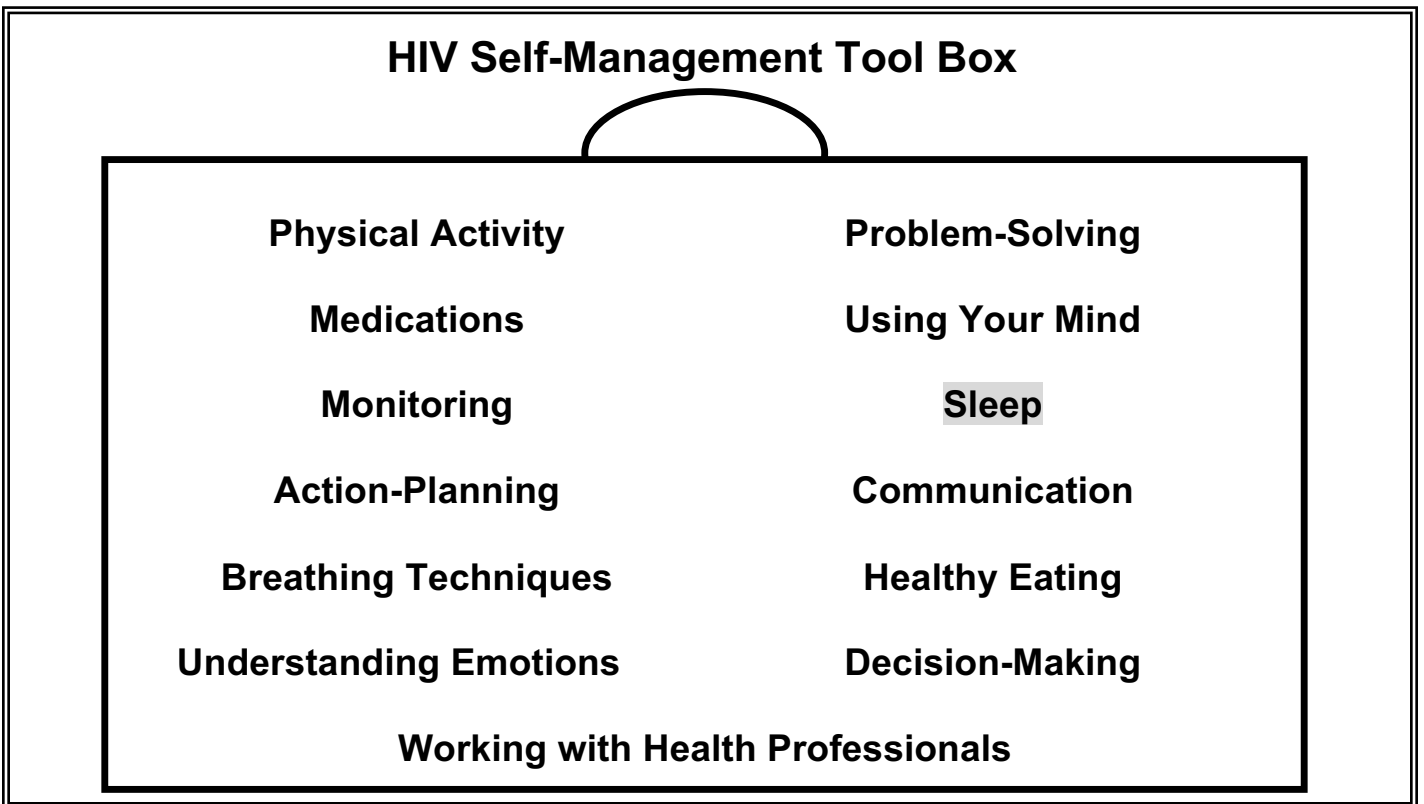


and be sure to add any of the following **if they are not mentioned**:

- Go to bed at the same time every night
 - Get up at the same time every day (even weekends)
 - Avoid caffeine (including chocolate) for 4 hours before bedtime
 - Avoid alcohol near bedtime – it interferes with the quality of sleep
 - If you are a light sleeper, use ear plugs
 - Avoid liquids near bedtime to avoid needing to get up to go to the bathroom
 - If you are having problems with your medication, speak with your healthcare provider.
5. **Say in your own words:** If you get to sleep okay, but find you wake and then have problems falling back to sleep, this may be caused by anxiety or depression.
6. **Say in your own words:** Sometimes you can fall back to sleep by keeping your mind off of your troubles. This is a time when you may want to practice a distraction similar to what we covered in an earlier session. If your sleep problems continue, or you are concerned about getting enough sleep, talk to your doctor.
7. **Say in your own words, pointing to “Sleep” on Chart 2:** Remember, “Sleep” is one of the tools in our Tool Box that we can use to break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



8. **Say in your own words:** Let's take a break now. When we return, we'll talk about making long-term plans for the future.



BREAK

20 minutes

Activity 4

20 minutes

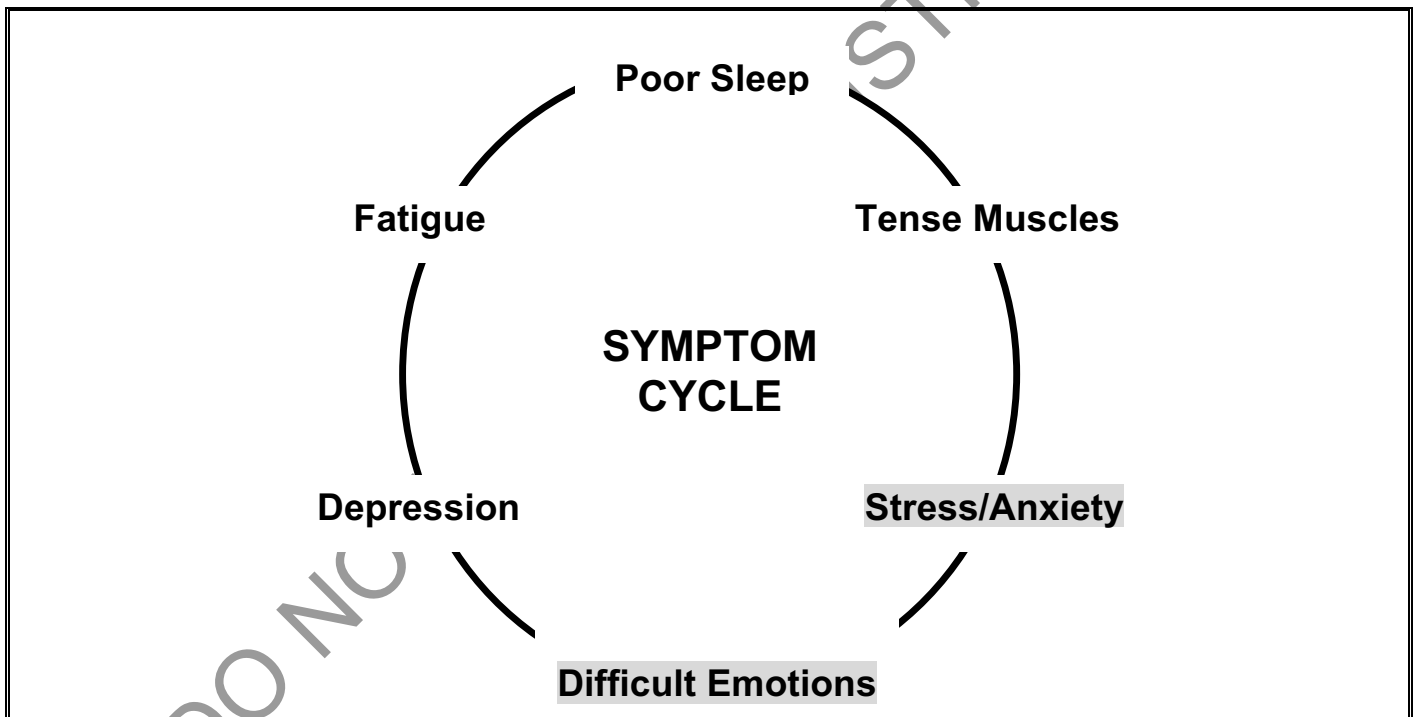
FUTURE PLANNING AND LEGAL ISSUES

Materials:

- Chart 2, “HIV Self-Management Tool Box”
- Chart 8, “Symptom Cycle”
- Chart 19, “Advance Directives”
- Chart 20, “Steps Toward Positive Thinking”

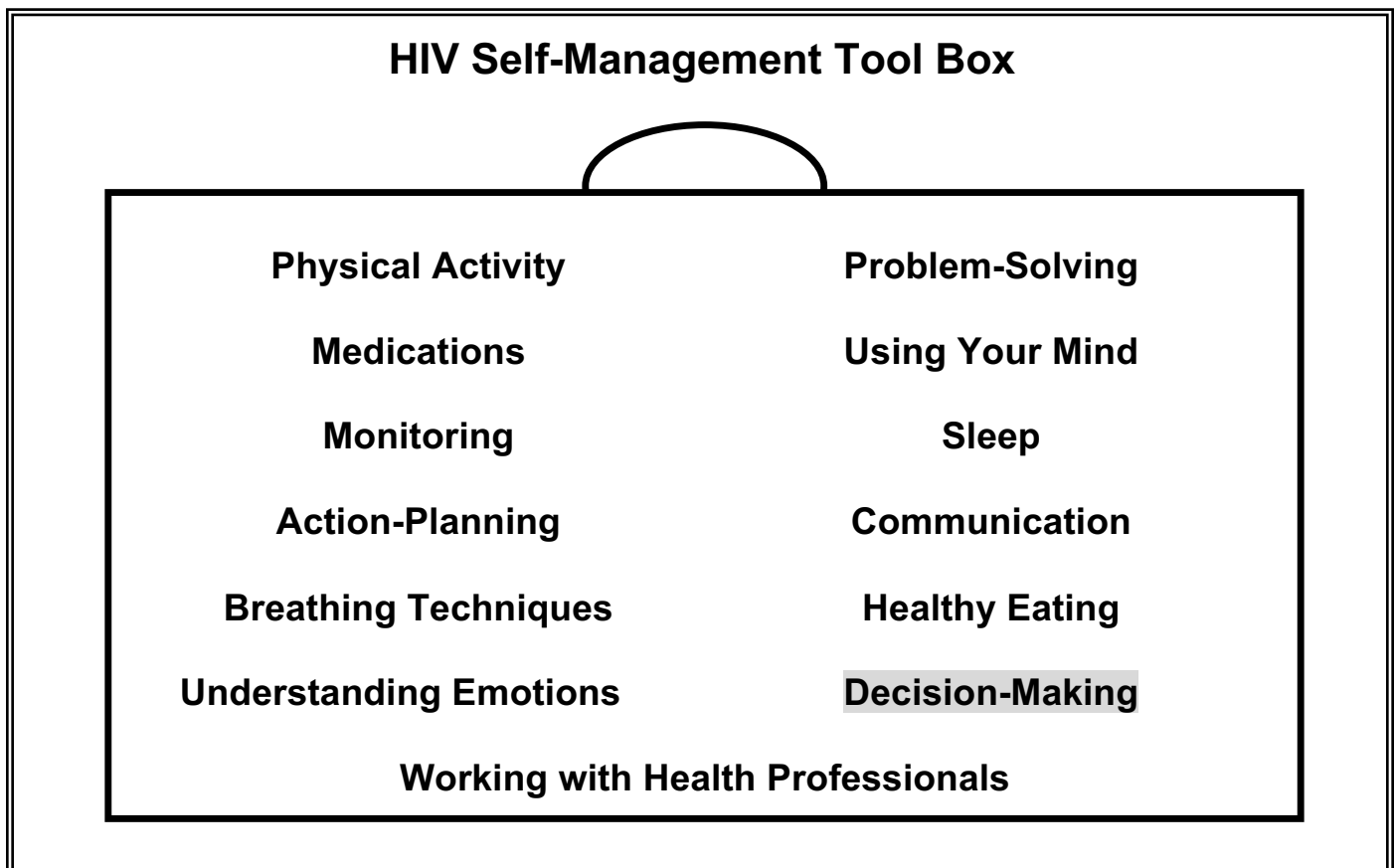
1. **Say in your own words, pointing to Stress/Anxiety and Difficult Emotions on Chart 8:** Many people living with HIV have stress, anxiety, and difficult emotions when thinking about the future.

Chart 8



2. **Say in your own words:** One way to reduce these fears about the future is to plan for it. We're going to look at two documents to help lessen those fears. This means making some decisions about the health care we may need when we are not well enough to make them ourselves at the time.
3. **Say in your own words, pointing to Decision-Making on Chart 2:** Making those hard decisions now can be a good self-management skill.

Chart 2



4. **Say in your own words:** We are going to discuss 2 documents. Both documents that we will be discussing are called “Advance Directives for Health Care.” Everyone, whether they have HIV or not, or are young or old, should have one of these documents. Accidents and illness can happen to anyone.
5. **Say in your own words:** The first document we are going to look at is called a **Living Will**. This is not the same document as a last will and testament. A Living Will applies when you are alive.
 - a. This document states your specific wishes about health care in the event that you are unable to express them yourself.
 - b. A Living Will can provide a general written statement of your wishes, and a guide to doctors on the life-saving treatments you may or may not want.
 - c. If you want your Living Will to set legal limits on the medical treatments you receive when you are unable to make decisions, you must sign the document, and have it signed by a witness.

6. **Say in your own words:** Now we will look at the second document, called **Power of Attorney for Health Care**. It is sometimes known as a **Health Care Proxy**. This is not the same as a plain power of attorney. The Power of Attorney for Health Care **only** applies to health care decisions.

a. Like the Living Will, the Power of Attorney for Health Care also states what types of medical care you want if you are unable to speak for yourself.

But it also gives someone you appoint, called your “agent” or “proxy”, the legal right to make decisions about your health and welfare if you are unable to make decisions for yourself. It can be anyone except your health care provider.

It also gives the proxy the legal right to see you in the hospital.

b. This document can apply at any time you are unable to speak for yourself, not just at end of life.

c. It is important to remember that anyone, young or old, ill or healthy, weak or robust, could find themselves in a position where other people have to make decisions about the medical interventions they are to have and how to manage their affairs.

7. **Say in your own words:** For an Advance Directive to be effective, there are 5 things you need to do:

(Chart 19 on the next page)

Advance Directives

1. **Decide on and express your wishes** (*and record them in the document*)
2. **Discuss with your family and your agent** (*if you are preparing a Power of Attorney for Health Care; this should be someone you trust, who is available and emotionally prepared to carry out your wishes. This can be a very difficult time for them, and some may be too emotional to carry out your wishes. Sometimes it's better to have an agent who is not a family member for this reason.*)
3. **Discuss with your doctors** (*and give a copy to all your doctors and hospitals*)
4. **Sign the document and have it witnessed**
5. **Keep in appropriate places** (*with all of your doctors, with your agent or proxy, at hospitals, at home, and carry a copy with you. Put it where it can easily be found – not in your safe deposit box. Emergency personnel often suggest that important health care documents be kept on or in your refrigerator and will look there.*)

8. **Say in your own words:** These two legal documents help us maintain control over our lives. They are easy documents to create.
 - a. The most important thing though, is to talk through these issues with those who are close to you. These are sometimes “hard” discussions, but you will relieve stress and anxiety for both you and your family.
 - b. Forms for this document can be found easily. You can probably get them from your health care provider, hospital, senior or community center, or on the internet.
9. **Say in your own words:** Some people find it difficult to get around to filling out a Living Will or organizing a Power of Attorney for Health Care.
10. **Say:** We're going to brainstorm: next:

What are some of the reasons that people don't prepare these documents?



Instructions to Leaders: Read back the list, ask for clarification.

11. Instructions to Leaders:

- Ask the group to choose 2 or 3 of the reasons from the list and problem-solve some possible solutions.
- Write the solutions on the board or flipchart
- Be sure to ask the participants who mentioned the difficulties if any of these suggestions were helpful.
- If so, encourage them to write them down for future reference.



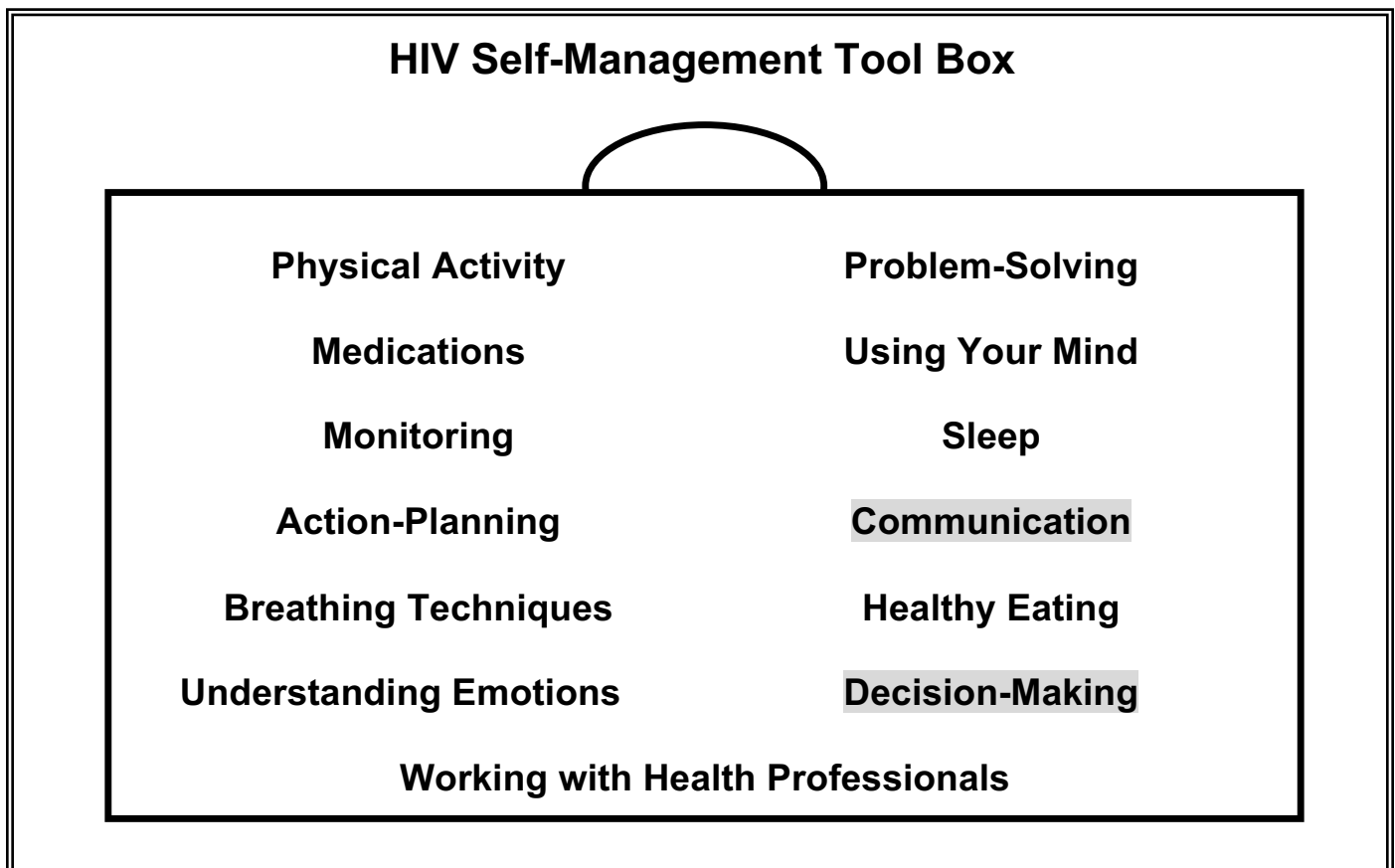
12. **Say in your own words:** As you can see, many of the reasons people don't prepare these documents are due to communication problems or feeling awkward about starting the communication process. We talked last week about improving our communication skills, and Chapter 16 in the book can give you tips.

One tip we can share with you is to have a “document party”, where everyone in the family comes together and completes these documents at the same time. This includes the young adults, too.

13. **Say in your own words:** Preparing an advance directive can be a great action plan!
14. **Say in your own words, pointing to “Decision-Making” and “Communication” on Chart 2:** Remember, “Decision-Making” and “Communication” are tools in our Tool Box that we can use to tackle future planning and break the Symptom Cycle.

(Chart 2 on the next page)

Chart 2



Activity 5

25 minutes

POSITIVE THINKING

Materials

- Chart 20, "Steps Toward Positive Thinking"

1. **Say in your own words:** All of us, whether we realize it or not, have habitual things we say to ourselves. Sometimes, we may even say these thoughts out loud.
2. **Say in your own words:** We also know that the mind can have a powerful effect on the way we feel. Therefore, when our thoughts are overly negative, they can lead us to feel and act negatively.
 - a. We develop a negative attitude or outlook that can create low self-esteem, depression, and inactivity; we want to give up. All of which makes our symptoms and health worse.

- b. For example, if the first thing we think about every morning when we wake up is how hard it is to get out of bed, the negative thoughts can actually make everything seem like an uphill battle, strewn with obstacles.
3. **Say in your own words:** Learning to change this negative thinking to more positive thinking is an important tool for managing our condition and related problems.
4. **Say in your own words:** Here are some examples of the same message presented in a negative way and then in a more positive way:

Instructions to Leaders: One Leader should read the negative and the other Leader the positive.

a. **Negative:** "I would like to exercise but can't. Just thinking about it makes me tired and short of breath. Besides I know that if I did any exercise, I won't be able to do what I used to. There is no reason to try. I know I can't do it."

Positive: "Starting an exercise program will give me an opportunity to get active again. I could start slow and set new goals for myself. If I get too tired, I can slow down or take a longer rest period"

b. **Negative:** "The future frightens me. My life will never be the same."

Positive: "The future is full of opportunities. You never know what may be around the corner."

5. **Instructions to Leaders:** After reading these examples, ask the group to share briefly how they felt when listening to each negative and positive message.



6. **Say in your own words:** As self-managers, learning to replace or change our negative thoughts and attitudes for more positive ones can help us to better manage our health and lives in general.
7. **Say in your own words:** We are now going to practice how we can begin to think more positively.

8. **Instructions to Leaders:** Ask the group for 2 or 3 examples of negative things they say to themselves or hear others say about themselves. **Do not make a long list—no more than 5.**



Be prepared to give personal ones (if possible, around HIV), if needed, or use the following examples to get started. List these on the board or chart pad.

Examples of Negative Thoughts:

“My life is over.”

“Nobody is going to love me now.”

“I’ll never be like I was before.”

“I’ll never be able to do the things I did before.”

9. **Instructions to Leaders:** Next, referring to the list, ask participants to give some suggestions for changing or replacing the negative statements with positive ones.

Be prepared to give personal ones, if needed, or use the following examples to get started.

Examples of Positive Thoughts:

“With the new meds, I can live a normal lifespan.”

“I met some great people at the support group”

“I can do a little bit each day.”

“Now, I can do new things, and maybe I can be better than before.”

10. **Say in your own words, referring to Chart 20:** Here are some steps toward positive thinking.

Chart 20

Steps Toward Positive Thinking

1. **Write down self-defeating thoughts** (*or irrational beliefs*)
2. **Change them to rational and helpful thoughts**
3. **Rehearse** (*mentally say these things to yourself so it is familiar*)
4. **Practice** (*in real situations*)
5. **Be patient** (*it takes time for new patterns of thinking to become automatic*)

11. **Say in your own words:** Sometimes, especially at the beginning, it is difficult to change these negative thoughts into positive ones.

- a. If this happens, it is helpful to have some ready-made positive statements or affirmations on hand to use, especially for those times we are really down.
- b. For example, have something good to say about yourself or the situation like, "I am an able person," "I'm feeling better about myself every day" or "Life is an adventure; there is always something new around the corner."
12. **Say in your own words:** Changing the way we think is like changing *any habit*. At first, we must be deliberate and pay close attention. With patience and practice, though, both positive thinking and a more positive outlook on life will become automatic responses, like learning to dance or drive a car.
13. **Say in your own words:** Let's take a minute to reflect on something positive about ourselves. Examples might be:

"I'm a competent person"

"I am a kind person"

"I try to help others"

"I am a hard worker"

Instructions to Leaders: Give them a minute to reflect. Ask for a couple of them to share their ideas.

Tell them that this can be their "positive thinking mantra, a statement to repeat and use when they may find themselves thinking negatively.

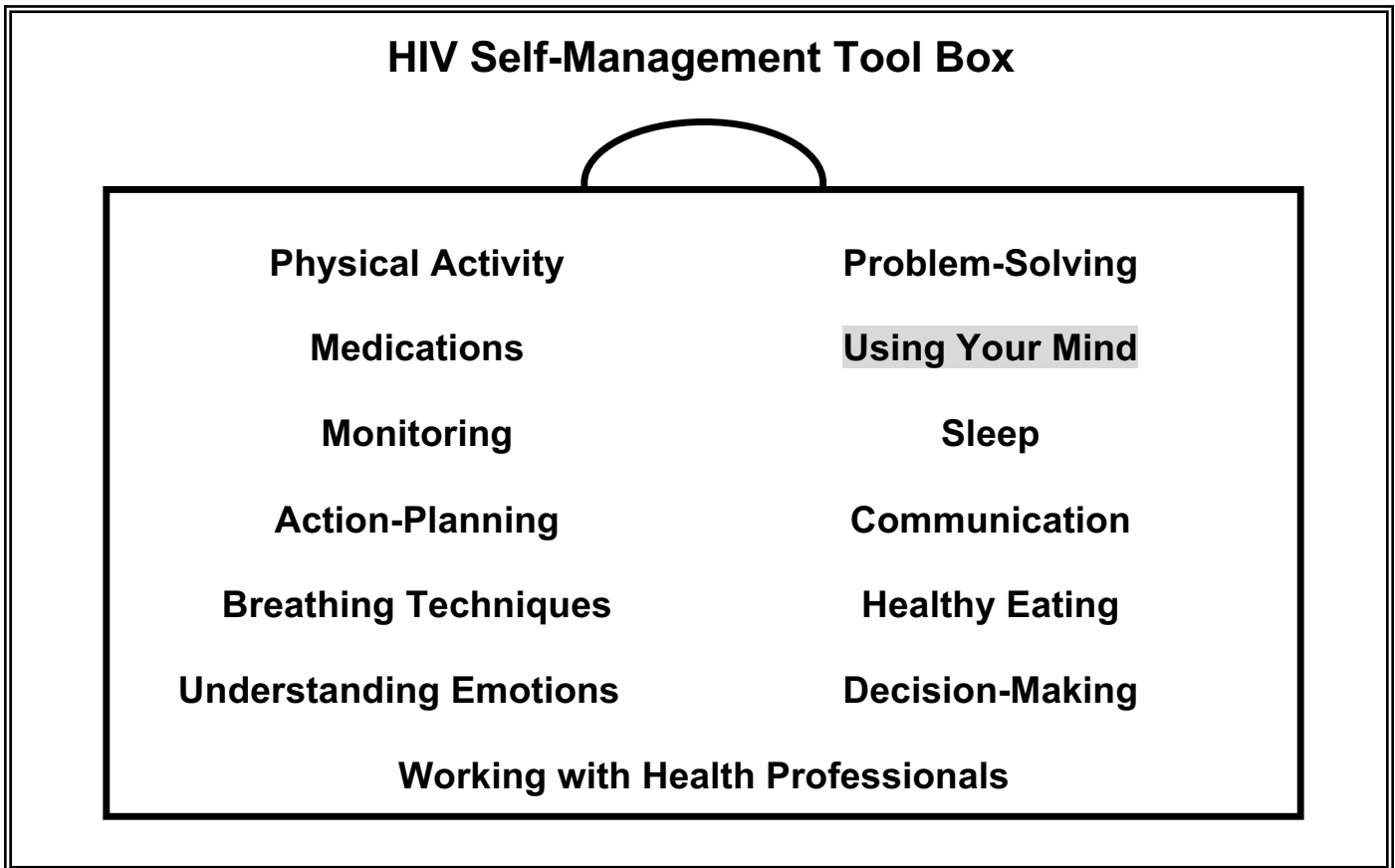
Invite participants to watch for negative thoughts (either in themselves or others) this next week and practice changing these to more positive thoughts.



14. **Say in your own words:** If after rehearsing and practicing for a number of weeks, positive thinking still doesn't seem to be working for you, don't worry. Rather, use another technique in the workshop or book to help manage your symptoms, and try again later to practice positive thinking.
15. **Say in your own words:** If you are feeling really down and this technique just doesn't seem to be helping, talk with your doctor. You may be depressed and need medication and/or counseling.
16. **Say in your own words, pointing to "Using Your Mind" on Chart 2:** Remember, positive thinking is one of the ways of "Using Your Mind" in our Tool

Box that we can use to break the Symptom Cycle.

Chart 2



Activity 6

MAKING AN ACTION PLAN

20 minutes

Materials:

- Chart 6, “Parts of an Action Plan”
- Action Plan Flow Chart, Appendix II

1. **Say in your own words:** Now it’s time to make our action plans for this week. This is something we will do each week

Remember that action plans allow us to achieve what we want or decide to do by breaking down the activity into smaller, more “doable” steps or tasks.

2. **Say in your own words, pointing at Chart 6:** Let’s hear everyone’s action plan, looking at parts 4 and 5 on our Chart:

Parts of an Action Plan

1. **Something YOU want or decide to do**
2. **Achievable** (*something you can expect to be able to do this week*)
3. **Action-specific** (*for example, gaining or losing weight is not an action or behaviour, but adding or avoiding snacks-between meals is; gaining or losing weight is the RESULT of actions*)
4. **Answer the questions:**
 - What?** (*the specific action*)
 - How much?** (*it's time, distance, amount*)
 - When?** (*time of day or days of the week*)
 - How often?** (*number of times in the week; avoid "every day"*)
5. **Confidence level of 7 or more** (*on a scale of 0=not at all sure to 10=totally sure*)

3. **Say in your own words:** We'll start with our own action plans for the week.

4. **Instructions to Leaders:** One Leader should go through each step on Chart 6 (pointing at each step while standing next to it), using their own action plan. Start by saying what you are trying to accomplish such as exercise more.

IMPORTANT
MODELING
MOMENT



PREPARE BEFORE SESSION: Leaders should prepare action plans in advance with each other, remembering that the Leaders' action plans will be **MODELS** for the rest of the participants. This means that your action plan should be something you really want to do and will complete.

5. **Say in your own words:** Now my partner will share their plan.

Instructions to Leaders: The second Leader reports their action plan, answering each of the questions on Chart 6 as the first leader points to them.

IMPORTANT
MODELING
MOMENT



6. **Instructions to Leaders:** Emphasise that action plans must be:

- something you **want or decide to do**
- **achievable**, that is you can expect to achieve it in the next week

7. **Say in your own words:** Please tell us your action plan for this week, and how sure you are that you will complete the plan, 0 being not at all sure and 10 being totally sure.

8. **Instructions to Leaders:** Ask for a volunteer to start reporting actions plans and then go around the room from that person (do not ask for a second volunteer).

Point to each step (what, how much, when, how often, confidence level) on Chart 5 as each participant reports their plan.

See Appendix II, Making an Action Plan Flow Chart for details.

9. **Instructions to Leaders:** If confidence level is less than 7, ask the participant what the problem might be and if they encounter the problem, what would they do.



Ask the participant if they would like suggestions from the group.

If they say yes, have the group offer 4-5 suggestions and the original participant should not comment.

After all the comments ask the participant “if you have (name the problem) what will you do?” Participants can change the plan if they wish.

Ask the participant to state the new or amended action plan, starting with “I will”.

10. **Instructions to Leaders:** If someone is having trouble writing a clear action plan (i.e., specific activity, times per day, days per week), go through the same steps as above, **asking other group members for suggestions** *before* you help.

Do not spend more than 3 minutes with any one person. If someone is having problems, work with them individually *afterwards*.

If someone does not want to make an action plan say that is OK and that you will come back to them later—then go back to the person after everyone has made their plan. If they still do not want to make a plan that is OK.

Activity 7

CLOSING

5 minutes

1. **Say in your own words:** Next week will be the last session, and we will be discussing **working with your health care professionals, building support systems**, and **sharing what we have accomplished**.

2. **Say in your own words:** In preparation, we would like you to do two things.
 - a. We would like you to call, email or write a letter to your doctor or health care provider about what you have accomplished during this workshop. If you are not pleased with your progress over the past 6 weeks, we would like you to write a letter to the developers of this workshop explaining your reasons. The address is:

Self-Management Resource Center
PO Box 219
Aptos CA 95001 USA
smrc@selfmanagementresource.com

You don't have to send or show these letters if you don't want to, but please bring them with you next week for your own use in the sharing activity. If you do send the letter to your doctor, though, it would really help to get the word out about the program.
 - b. While we won't be setting a weekly action plan next week, we will be looking at longer term plans. Therefore, we would like you to start thinking of a goal for the next 3 to 6 months and consider how you might break it down to achieve it.

3. **Instructions to Leaders:** Remind participants that they may wish to support each other's progress and action planning during the week.

4. **Instructions to Leaders:** Remind participants to pay attention to the type of thoughts they have about themselves, and to try to replace the negative ones with positive ones.

5. **Instructions to Leaders:** Ask group if they want to exchange addresses and telephone numbers. If so, ask for a volunteer to coordinate getting the list

compiled and photocopied. If someone does not want to be on the list, assure them that they don't have to. Do NOT offer to do this for them! (This is a self-management workshop!)

7. Instructions to Leaders: Collect name tags.

8. Instructions to Leaders: Stay around for a few minutes to answer questions and clean up.

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Purpose

- To give participants skills in working more effectively with their health care providers
- To discuss strategies for managing a healthy weight
- To discuss ways that participants can build support systems and find community resources
- To assess progress and acknowledge accomplishments
- To integrate the skills learned in this workshop into plans for the future

Objectives

By the end of this session, group members will be able to:

1. Name at least two strategies for working effectively with their health care providers
2. State their role in the care of their condition
3. State what the 200 calorie a day plan is for weight management
4. Identify at least three steps towards developing personal support
5. Identify at least three means of finding community resources
6. State their self-management accomplishments.
7. Set a personal goal for the future.
8. Make a plan for dealing with HIV in the future.

Materials

- Charts:
 - 2: HIV Self-Management Tool Box (**post at all sessions**)
 - 3: Guidelines (**post at all sessions**)
 - 4: Brainstorming (**post at all sessions**)
 - 6: Parts of an Action Plan (**post at all sessions**)
 - 7: Problem-Solving Steps (**post at all sessions**)
 - 8: Symptom Cycle (**post at all sessions**)
 - 12: Take P.A.R.T.
 - 21: Maintaining a Healthy Weight
- Name tags
- Flip chart/felt pens
- *Living a Healthy Life with HIV*
- Pad of paper, extra pencils
- Tissues
- Workshop evaluation forms (optional).

- Completion certificate for each participant (optional).

Homework Assignments Given During Session 5

- Reading: *Living a Healthy Life with HIV*, Chapter 6, pages 238-239

Reading for Leaders' Preparation:

- *Living a Healthy Life*: as homework assignment, above
- Making an Action Plan Flow Chart, Appendix II
- Feedback Flow Chart, Appendix II

Agenda

Post this agenda at the beginning of meeting:

Session Six Agenda

- Activity 1: Feedback (20 minutes)
- Activity 2: Working with Your Health Care Provider and Health Care System (25 minutes)
- Activity 3: Weight Management (20 minutes)
- BREAK (15 minutes)
- Activity 4: Building Support Systems (20 minutes)
- Activity 5: Looking Back and Planning for the Future (40 minutes)
- Activity 6: Closing (5 minutes)

Activity 1

FEEDBACK/PROBLEM-SOLVING

20 minutes

Materials

- Feedback Flow Chart, Appendix II

Instructions to Leaders: Encourage participation of all members. Not more than 3-5 minutes should ever be spent on one person. People who discuss their action plans earlier will probably need more time than those who come later. Do not spend all of your time with "yes buts" or other "real" problem people (the general rule is that if someone has said "yes but" three times, you should go on to someone else. Deal with these folks during the break. Please review the **Feedback Flow Chart in Appendix II** to help you make appropriate responses to each participant.

1. **Say in your own words:** Welcome back! The first thing we're going to do today is to report back on the action plans we made last week. Each of us will share our experiences in completing our action plans.

I'll start, and then my partner will report.

Instructions to Leaders: Start with yourself as a model but make it very short. Be sure one Leader models a plan that has been accomplished, and the other where a modification was made and then completed.

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2. **Say in your own words:** Now we'd like to hear about your action plans. We'll start with a volunteer and then go around the room.
 - a. First, tell us what your action plan was for the past week.
 - b. Then tell us how well the action plan was accomplished. You can use words like:
 - accomplished
 - partially accomplished
 - was not able to accomplish
 - changed it to another plan

Sometimes plans need to be changed and if this occurred and you substituted something else, this is good self-management.

- c. Finally, if you were not able to accomplish your plan or if you changed your plan, describe the barriers that prevented you from completing your action plan or caused you to change it. If you changed it, tell us how you changed it.

3. Instructions to Leaders: Respond to each participant as follows

In addition to the following instructions, make sure you review the Feedback Flow Chart in Appendix II.

If someone reports their confidence level ↓	If they were successful ↓	If they met obstacles and adjusted or changed their action plan successfully ↓	If there were problems and the person was partially successful ↓	If there were problems and the person was unsuccessful ↓
tell them that we don't need to report confidence levels from last week	congratulate them	congratulate them for being a good self-manager	comment on the good start they have made (but do not congratulate), and then problem-solve (see problem-solving steps below) with the group, if the person wishes to do so	go through the steps of problem-solving:

Problem-solving Steps with the group:

STEP 1

Ask the person to state the problem he/she had in completing the plan. Ask them to be specific.



STEP 2

Ask the person if they have any ideas of how to solve the problem or did they try a solution. Stop here if the person has ideas or has already tried a solution.

STEP 3

If the problem is not solved, ask the individual if they would like to hear some suggestions from the group on how to solve the problem. If yes, then continue with the brainstorm in the next steps. If not, move on to the next participant.

STEP 4

Ask the group to give **4 or 5 possible solutions**. These suggestions should be given without comment or discussion. Refer to Chart 4 (Brainstorming) to remind people.

STEP 5

Tell the person with the problem that they just listen and get ideas. The group leaders can also offer suggestions, but *not until* others in the group have participated.

STEP 6

When you have 5 possible solutions stop the brainstorm, or if you see there are more ideas, tell the group that you'll take one more and then stop the brainstorm. Suggest that they catch the person at break.

Leaders may write these on the flip chart or suggest that the person with the problem do so. If you suspect that your group may have people who cannot read, suggest that they remember the ideas instead of writing them down.

STEP 7

Ask original participant if they could use any of the strategies suggested and, if so, which one. Recommend that participant make a note of the helpful suggestion or remember it.

If no suggestions seem workable, then say you will talk with the person more during the break - and do so.

REMEMBER, DO NOT SPEND A LOT OF TIME ON ANY ONE PERSON. AFTER THREE "YES BUTS," GO ON TO THE NEXT PERSON.

Activity 2

25 minutes

WORKING WITH YOUR HEALTH CARE PROVIDER AND HEALTH CARE SYSTEM

Materials

- Chart 12, “Take P.A.R.T.”

1. **Say in your own words:** We can do many things to manage HIV, but obviously we can't do it all on our own. Being a good self-manager means working closely with our **entire** healthcare team – which may include clinics, consultants, nurses, GPs, dentists etc.
 - a. We know that it's important to keep our health care providers informed about our medication, symptoms and side effects, but keeping the doctor informed is only one part of working with our healthcare team.
 - b. As with any relationship, the relationship with our health care providers takes ongoing attention. Also, ensuring that we are getting good health care can sometimes be difficult.
 - c. There are really two types of problems. One has to do with the health care system, for example, getting through on the telephone or getting an appointment. The other type of problem relates to working *directly* with health care providers. Let's look at both.
2. **Say:** Let's brainstorm.

What general problems do you have with your health care organization or system?



Instructions to Leaders: When finished, read back the list, ask if any need clarification, and add the following if not mentioned:

- Long wait in waiting room
- Takes too long to get an appointment
- Too little time with health care provider
- Automated phones; can't talk to a person when needed
- Never see the same doctor

- Difficult to get prescription refills

3. **Say:** Now another brainstorm:

What general problems do you have with your *health care provider* – your doctor or other person giving you care?



Instructions to Leaders: Read over the list and ask if any need clarification. Be sure to add any of the following if they were not mentioned:

- Uses technical words; doesn't understand
- Doesn't explain my medications, tests, and so on
- Too quick to prescribe
- Never listens
- Always in a hurry
- Ignores my ideas
- Don't feel comfortable with them
- Can't get back test results

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4. **Instructions to Leaders: Problem-solve** 1 or 2 of the problems from each list.

Ask the group to brainstorm *possible solutions*. Write these on the board or flip chart or suggest that the person with the problem write them down. *These suggestions should be given without comment or discussion*. Leaders can also offer suggestions, but *not until* others in the group have participated.



Ask if the participant who reported the problem can use any of the suggestions, and if so, which one. Recommend that the participant make a note of the helpful suggestion(s). (Remember the "Three yes-buts . . . and you're out" rule.)

5. **Say in your own words:** One way to work with health care providers is to use “I messages”. This means reporting on how the actions of someone else make you feel. For example, “when I have to wait a long time, I feel angry and frustrated.”
6. **Say in your own words:** Remember that health care providers have problems, too. They work under many constraints, such as time limits and lack of information (that's why it is so important to keep them informed about our condition). They are just as frustrated as we are.

7. **Say in your own words:** To use the time we have most effectively, it is good to bring up concerns we might have at the beginning of the appointment rather than waiting until you are on the way out the door to ask questions.
8. **Say in your own words, using Chart 12:** In order to work effectively with the members of our health care team, we will review the **Take PART** chart that we looked at in session 3:

(Chart 12 on next page)

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Take P.A.R.T.

Prepare

- **Keep track** *(of your symptoms; monitor what's going on between visits to your health care provider. For example, are symptoms better, worse or the same; are changes slow or rapid; has anything changed in your life to affect you. Be sure to write this down, along with what you do to manage the symptoms, and whether or not it helped. This will help you spot trends or patterns in your condition.)*
- **Report** *(on your symptoms, changes and patterns in between visits. Also report on any medications or other treatments you are using, and their effects.)*
- **List** *(your MAIN concerns or questions. Ask these at the beginning of the visit. If you have more than 2 or 3 questions, give the whole list to your provider, but do not expect answers to more than 2 or 3 during this visit. Your health care provider should see the whole list, however, because something that may not seem important to you may be important medically.)*

Ask *(questions about your diagnosis, tests, medications and follow up.)*

Repeat *(back to the health care provider key points discussed during the visit, like diagnosis, what to expect, next steps, treatment actions, etc. This gives both of you an opportunity to correct any miscommunications. It is also a good idea to take notes so you can remember exactly what was discussed and what you agreed to do.)*

Take action *(If there are barriers to your following your provider's recommendations, let the doctor know. Ask for written instructions, if appropriate. If you are not given written instructions, write yourself an action plan for what you will do to follow-up the visit.)*

9. **Say in your own words:** Our health care providers can sometimes feel frustrated by the complexities of HIV, too. Remember that they are people and need to know they are appreciated as well. A kind word and a simple “thank you” now and then can help both sides of the communication process.

Activity 3

WEIGHT MANAGEMENT

20 minutes

Materials

- Chart 21, “Maintaining a Healthy Weight”

1. **Say in your own words:** Maintaining a healthy weight can be a challenge. Obesity is becoming more common in people with HIV. It can cause other health problems, such as type 2 diabetes, high blood pressure, heart disease, and an increase risk for developing certain cancers.

On the other hand, weighing too little can weaken your immune system and possibly lead to bone problems and lack of energy.

2. **Say in your own words:** Many of us would like to make changes in our weight. Most of us would like to lose weight but some of us may want to gain weight.

In order to do either of these things, we have to know what we are doing now. For two days this past week we asked you to keep a food diary. Now we would like you to share what you learned.

3. **Instructions to Leaders:** Ask for volunteers. If no one volunteers immediately, just wait. If after 30 seconds, no one volunteers, each of the Leaders can say something and then ask for volunteers again.



4. **Say in your own words:** As you can see, we can learn a lot by just observing our own behavior. Let's take a moment now and go over some basics of weight management, but even then, what we eat and the energy we use is important.
5. **Say in your own words:** For most people, how much we weigh depends on how much we eat and how much energy we use. Our genetics can also influence our weight.
6. **Say in your own words:** Earlier in this workshop we talked about exercise and how to increase our physical activity. However, although exercise helps greatly with weight management, we also need to watch what we eat. Here are some suggestions:

Maintaining a Healthy Weight

1. Pay attention to portion size (*Larger portions make it harder to lose weight and can also lead to weight gain, while smaller portions can help lead to weight loss.*)

2. Use the plate method of choosing foods

(Ask: *Who can remember what a plate should look like? Remember that there is also a Diabetes Plate in the book.*



Instructions to Leaders: Have participants give answer and, if they cannot, you do it. At each meal, your plate should be about:

- *a little less than a fourth fruit*
- *a little more than a fourth vegetables*
- *a little more than a fourth food made from grain: bread, tortilla, grits, pasta, rice etc.*
- *a little less of a fourth protein from either lean animal or plant sources*
- *to this you can add a glass of low-fat milk or some other dairy product like yogurt*

3. Limit foods with more than 5 grams of fat per portion (*Avoid foods with saturated or trans fats.*)

(Ask: *Who can tell me how to identify fats we should avoid?*

(Answer: *Those that are solid at room temperature.)*



4. Eat 5-7 portions of fruit and vegetables a day

5. Drink water or broth-based soups (*These foods tend to be filling and help you eat less during the meal. If you are trying to gain weight, have these at the end of the meal.*)

6. Plan your meals and snacks and plan for regular eating times (*Grazing and just grabbing the first food you see tends to lead to weight gain*)

7. Eat breakfast (*People who eat breakfast find it easier to lose weight.*)

7. **Say in your own words:** Changing weight is not something we can do in a hurry. If we take small steps, we can make big changes.

One way to do this is the 200 calorie a day plan. You all know how to keep track of exercise and how to use a food diary to keep track of what you eat.

If each day we burn about 100 extra calories of exercise (this is about 20 minutes) and we reduce about 100 calories of food (this is a slice of bread or a small cookie), over a year's time this can add up to 20 pounds of weight loss.

Of course, if you are trying to gain weight you should not cut down on your exercise, but you should add 100 to 200 calories a day to what you eat. This may be challenging. You may eat several times a day and eat high calorie food, solid or liquid.

8. **Say in your own words:** These recommendations work for most people, but if this doesn't work for you, get some help. Two good resources to start with are your health care provider and a Registered Dietitian (R.D.).
9. **Say in your own words:** Remember, there is a lot of information about healthy eating in your book.



BREAK

20 minutes

Activity 4

20 minutes

BUILDING SUPPORT SYSTEMS

Materials

- None

1. **Say in your own words:** We all know that with HIV and the complexities of its medical management no one can do it well alone. It is important to have the personal support, as well as services and resources to help us manage better.

This includes things such as having someone around us who can remind us to take our medication or having someone to talk to when we are feeling down.

In either case, part of being a skilled self-manager is knowing how to get help and support when we need it. And we need to know where to look for that support, accepting that often it may come from unexpected places. Building such a support system, however, is not always easy because the problem is when we need help, we often don't know how to get it.

2. **Say:** Let's brainstorm. This is the question is:

What are some of the obstacles that make it difficult to develop a support system?



3. **Instructions to Leaders:** Read back the list and ask if any need clarification.

Problem-solve 1 or 2 of the problems from the list.

Ask the group to give possible solutions. Write these on the board or flip chart or suggest that the person with the problem remember them or write them down. These suggestions should be given without comment or discussion. Leaders can also offer suggestions, but not until others in the group have participated.

Ask if the participant who reported the problem can use any of the suggestions, and if so, which one. Recommend that the participant make a note of the helpful suggestion(s). (Remember the "Three yes-buts . . . and you're out" rule.)



4. **Say in your own words:** Sometimes we will need to look for support beyond our friends, family and partners. Support can be found from other people and in other places
5. **Say:** Let's brainstorm again. The question is:

Where could we find other support?

Instructions to Leaders: Read back the list, ask if any need clarification, and add the following if not already mentioned:

- People from this program
- HIV volunteer agencies, such as Project Inform or the AIDS Foundation
- Other volunteer agencies working outside of the HIV community
- Ethnic or community support groups



- Religious groups
- Medical centers
- Visiting nurses
- Service clubs, youth groups, and so on
- Adult education centers
- Internet

Note to Leaders: Ensure information from your region is available, including contact numbers. This information, cleared by your organization's coordinator, may be placed on a resource table at the back of the room. Do not hand out information during class or provide informational materials yourself.

6. **Say in your own words:** Because of the way the HIV epidemic developed over time, many people with HIV still look only to the HIV community for support. We want to encourage you to expand your thinking about the possible sources of support. Think beyond the HIV community and your own family. There are resources and wonderful people out there who would be happy to give support if asked. But you have to ask.
7. **Say in your own words:** The search for support or services is not a linear process, but one that involves trying different things at the same time, rather than one at a time. Also, sometimes one contact may lead to many resources, all of which are important to follow-up with. You never know when you may need that information, resource, or service. Therefore, it is useful to write these contacts and resources down for the future.
8. **Say in your own words:** Finally, one way to gain support is to *give* support. Let's brainstorm.

What kinds of things can you do to give support?

Instructions to Leaders: Read back the list and ask if any need clarification.



9. **Say in your own words:** Again, be creative in looking for and offering support. Both can be a gift – to receive and to give.

Activity 5

LOOKING BACK AND PLANNING FOR THE FUTURE

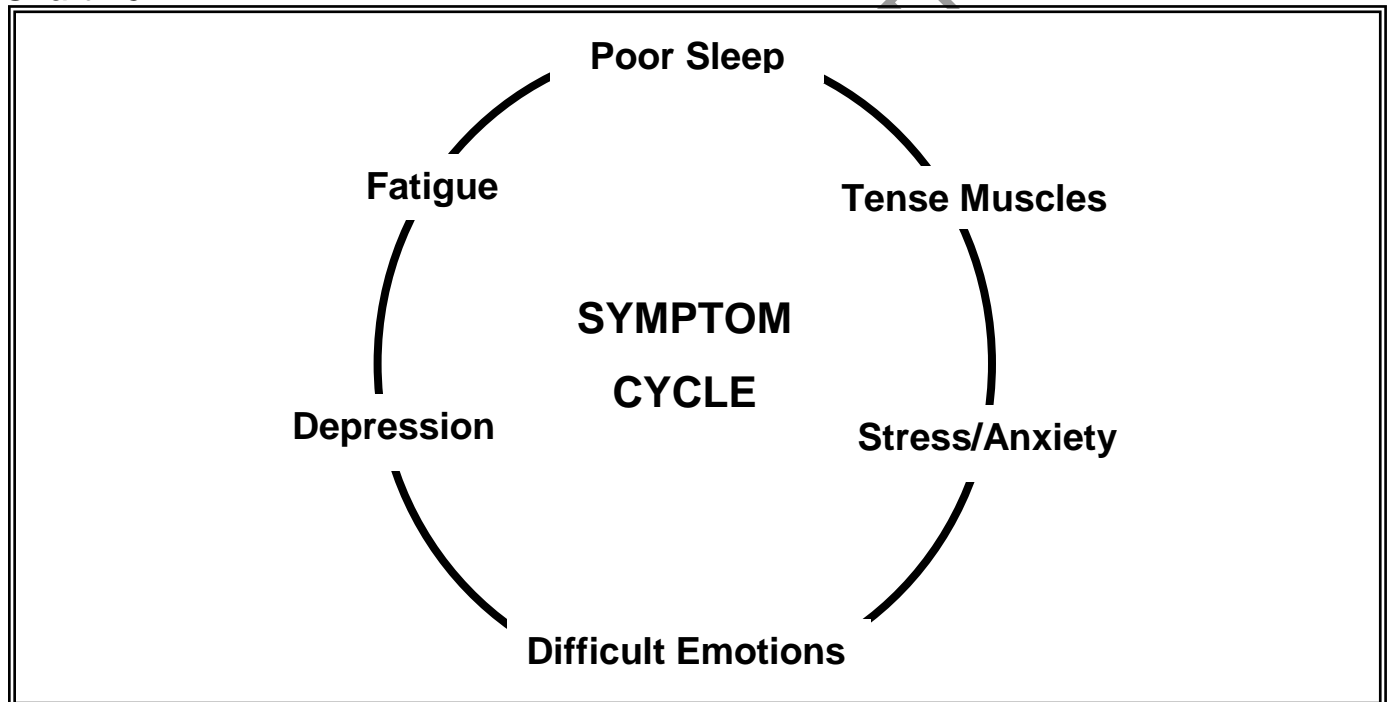
40 minutes

Materials

- Chart 2, “Self-Management Tool Box”
- Chart 10, “Symptom Cycle”

1. **Say in your own words, using Charts 10 and 2:** As we have said throughout this workshop, having HIV, or being close to someone who has, can create a vicious cycle of symptoms. Each symptom can make the others worse; this, in turn, causes problems that make our lives more difficult to navigate.

Chart 10



2. **Say in your own words:** However, we've also stopped to examine ways to manage these problems and break the Symptom Cycle at different points.
3. **Instruction to Leaders:** Invite the group to **call out** what self-management tools we have learned in the workshop. You do not need to write these down.

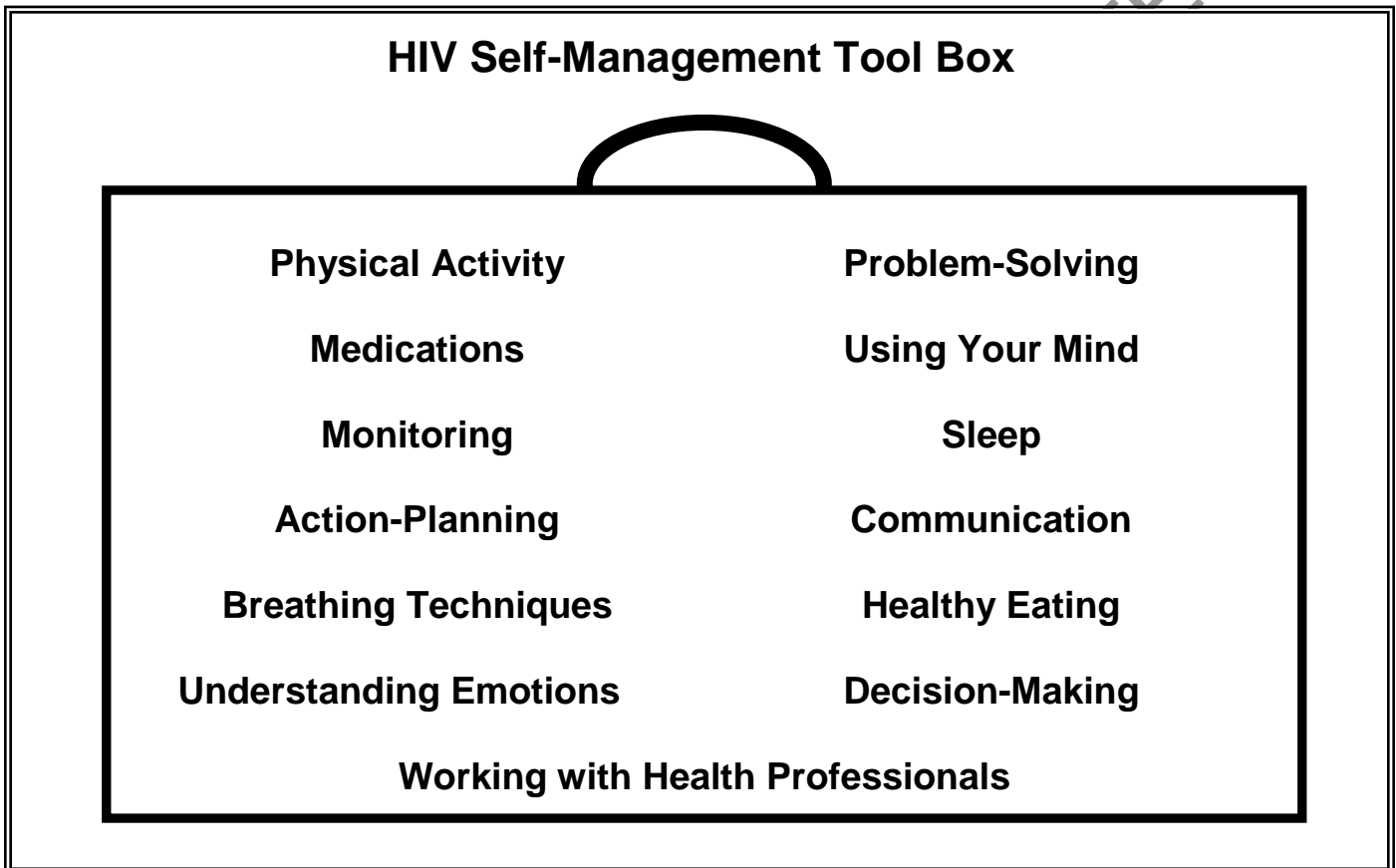


4. **Instructions to Leaders:** Using **Chart 2**, discuss briefly how these different tools can be used to break the Symptom Cycle.

For example, Physical Activity can break the cycle at almost any point: the techniques to manage symptoms through the mind can break it at fatigue, stress, difficult emotions, etc.

Problem-Solving, Decision-Making and Action Planning are the basic tools in everyone's HIV Tool Box. These make the other tools possible

Chart 2



5. **Say in your own words:** You do not have to use **all** the tools here. Rather, we may find one, two, or three things that work well for us in breaking the cycle.

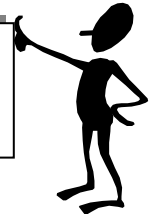
- Something may work better at one time than it does at another, so there are a variety of tools we can choose from, depending on the circumstances at that time.
- Once the cycle is broken, it is broken – but it often repairs itself. When that happens, you can just go back and break it again!

6. **Say in your own words:** Now, let's take a few minutes to think about what steps we'll take next in managing our health problems.

Say: What are your goals for the next three to six months and what are some of the steps will you take to reach these goals?

Instructions to Leaders: Leaders should start this process by stating their goals, how they plan to get there, and their confidence level.

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7. **Instructions to Leaders:** Ask for a volunteer to start, and then go around the room. Have participants state:

- their next goal
- the specific steps they plan to take toward reaching their goal
- and how sure they are that they can accomplish the goal on a scale of 0-10

8. **Instructions to Leaders:** If someone is not confident, have the person identify any anticipated problems, barriers or setbacks they may encounter. Choose one to three problems from those who are *not* confident (depending on time) and have the group help identify solutions.



9. **Say in your own words:** Now we'd like to go around the room and share with each other what we have **accomplished** during this workshop.
- a. You may use the letter you wrote to your health care provider, if you'd like. Remember you do not need to mail these letters or show them to anyone if you do not want to.
 - b. If anyone notices anything else that a person has accomplished, please speak up after they have shared.

10. **Instructions to Leaders:** Ask for a volunteer to start and then go around the room.

11. **Say in your own words:** We want to point out that everyone in this workshop has made one very important accomplishment: **you have helped each other.** If we can help someone else along a rough path, we aren't as aware of the

difficulties on our own path. People who help other people are happier and healthier. We can all find ways to be useful to others in our lives.

12. **Instructions to Leaders:** Ask the group to *applaud* themselves and each other as acknowledgement of their progress.
13. **Say in your own words:** Now we are going to do a short visualisation exercise to help reinforce our positive feelings about the progress we have made during the last six weeks. We are going to visualise ourselves successfully fulfilling the plans we just made for the future.
14. **Instructions to Leaders:** Read the following script slowly, and remember to pause when you see the dots (. . .):

Close your eyes . . . breathe deeply three times . . . in through your nose and all the way down to your abdomen, and then out slowly through pursed lips . . .

Think about your progress and your many accomplishments during the last six weeks . . . Each week you reported success in completing your action plans and used your problem-solving skills to make the changes you needed to reach your weekly goals . . . You took time to explore new ways to use your mind with activities like distraction . . . positive thinking . . . to help you deal with the rough spots on your path . . . You learned more about healthy eating. . . better sleep . . . and discovered new exercises . . . to add to your healthy habits. . . And you learned more about working with your health care team . . . And you shared your knowledge, experience and skills, and supported and helped each other along the way . . . These are your many accomplishments . . . Now, watch yourself as you successfully complete the steps you need to take to fulfil your future plans . . . *(pause 30 to 40 seconds)* . . . Think about how good you feel being able to do this . . .

Now take three more deep breaths and, when you are ready, open your eyes.

CLOSING

1. **Instructions to Leaders:** Ask participant who arranged it to pass out phone lists (if requested in Session Five).
3. **Instructions to Leaders:** Encourage participants to continue calling each other for support.
4. **Instructions to Leaders:** Remind participants to continue making action plans as part of their self-management program.
5. **Instructions to Leaders:** Stay around for a few minutes to answer questions and clean up. (Optional: You may end with a small party if you wish, but not until the session is over, and if the owners of the premises allow this.)
6. **Instructions to Leaders:** Turn in attendance sheet to sponsoring organisation.

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APPENDIX I: Charts, Agendas, Handout

Charts for the workshop are shown with the required content only.

We recommend that leaders make their own charts. This helps the leader know the workshop content better. They do not need to be “professional” looking.

Charts should be easily readable from across the room. For that reason, we recommend the use of the standard-size chart pads, about 27” X 32”.

Do NOT use overheads or PowerPoint. These require reduced lighting and make noise. They also take the focus away from the group and separate the leaders from the group. Besides, you never know when the bulb will burn out!

Tips about charts:

- There are “static” chart pads made of lightweight plastic that are ideal. The sheets cling to walls without tape. Permanent markers do not bleed through, and they can also be used with erasable whiteboard markers for brainstorming, etc. They can be rolled up easily and carried. They are a little more expensive than paper. They last longer than paper, too, but care must be taken not to tear them.
- If you use paper chart pads, there are some that have a light blue grid printed on them. The grid enables you to print on a straight line, as well as to figure out spacing.
- Do not use light color marking pens. Colors like yellow, orange, or light blue are not readable unless you are very close to them. Black, brown, dark blue, red, dark purple, dark green pens will show up the best.
- The material in your Leader’s Manual shown in italics with the chart can be added to the chart with light pencil or on Post-Its. They can only be seen by the leader that way, and will keep the chart simple from the participant’s view.


Chart 1

HIV Self-Management Tasks

- 1. Take care of health condition**
- 2. Carry out normal activities**
- 3. Manage emotional changes**

Chart 2

HIV Self-Management Tool Box



Physical Activity	Problem-Solving
Medications	Using Your Mind
Monitoring	Sleep
Action-Planning	Communication
Breathing Techniques	Healthy Eating
Understanding Emotions	Decision-Making
Working with Health Professionals	

Chart 3

Guidelines

- 1. Come to every session**
- 2. Be respectful of others and their ideas**
- 3. Maintain confidentiality**
- 4. Give any new activities at least a two-week trial**
- 5. Make and complete a weekly action plan**
- 6. Turn off your cell phones and other electronic devices**

Chart 4

Brainstorming

- Anyone can share**
- No commenting during brainstorm**
- No questions until after**
- Clarification waits until after**

Chart 5

HIV Monitoring Tests

T-Cell or CD4 count

- 500-1800 – normal
- 200-500 – weakened immune system
- Below 200 – danger of opportunistic infections

Viral Load

- Under 40-50 – undetectable
- Fewer than 10,000-30,000 – low but detectable
- About 100,000 – high
- Over 1,000,000 – very high

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Chart 6

Parts of an Action Plan

- 1. Something YOU want or decide to do**
- 2. Achievable**
- 3. Action-specific**
- 4. Answer the questions:**
 - What? (specific action)**
 - How much? (time, distance, amount)**
 - When? (time of day or which days of the week)**
 - How often? (number of days in the week)**
- 5. Confidence level of 7 or more**

Chart 7

Problem-Solving Steps

- 1. Identify the problem**
- 2. List ideas**
- 3. Select one**
- 4. Check the results**
- 5. Pick another idea**
- 6. Utilize other resources**
- 7. Accept that the problem may not be solvable now**

Chart 8

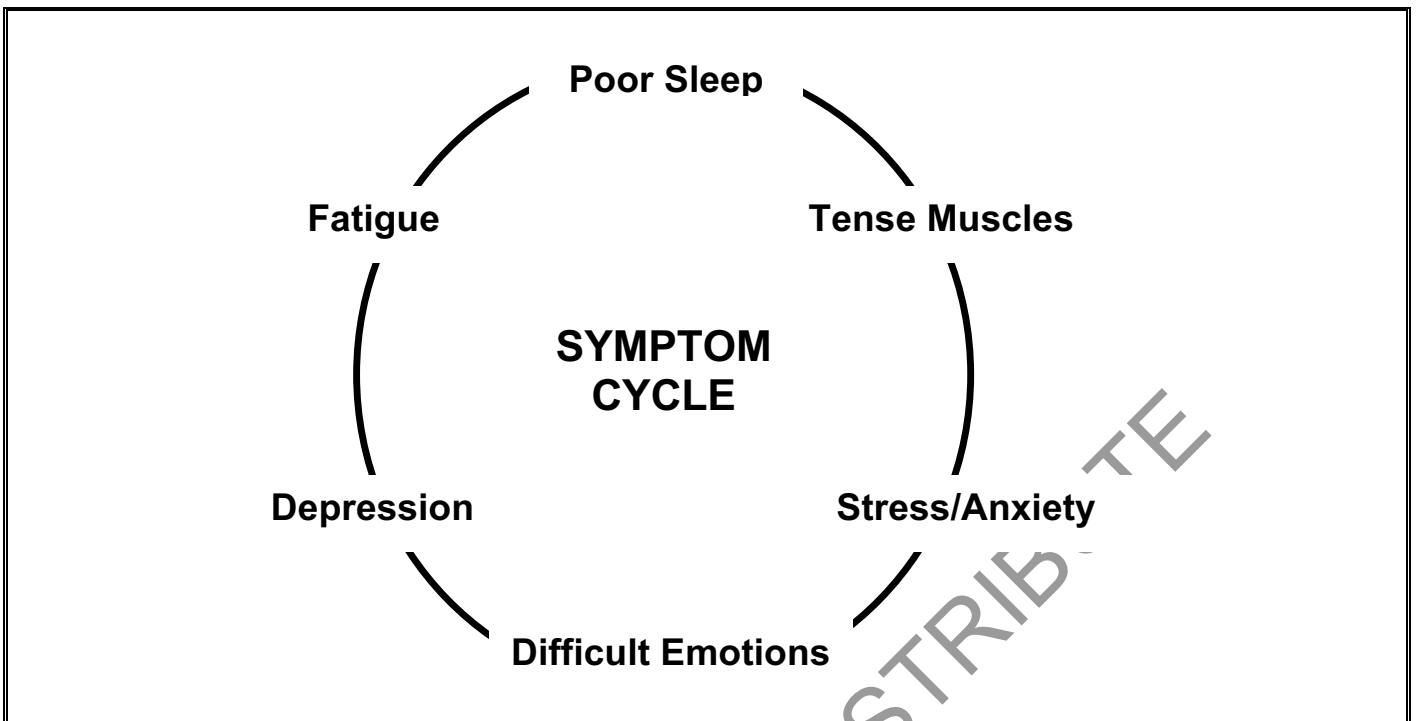


Chart 9

- ### Decision Making Steps
1. Identify the options
 2. Write down the “Pros” and “Cons” for each option
 3. Give a score to each statement from 1 being not important to 5 being very important
 4. Add each column and compare the results to find the higher score
 5. Ask yourself how this option meets the “gut test”

Chart 10

Example of Decision to be Made:

“Should I join a support group?”

<u>Pro</u>	<u>Score 1 - 5)</u>	<u>Con</u>	<u>Score 1 - 5)</u>
It might make me feel better	5	There may be people who I know	4
I will meet new people like me	4	It could be depressing and focus on negative things	1
It will help me learn about HIV and find out up to date information	5	Initially it's too hard to go as I'm scared	4
		The timing of the group may not work	2
<u>Pros Total</u>	<u>14</u>	<u>Cons Total</u>	<u>11</u>

The “Pros” total is greater than the “Cons”

Decision result is: To join a support group

Ask the question: “Does this meet the ‘gut test’?”

Chart 11

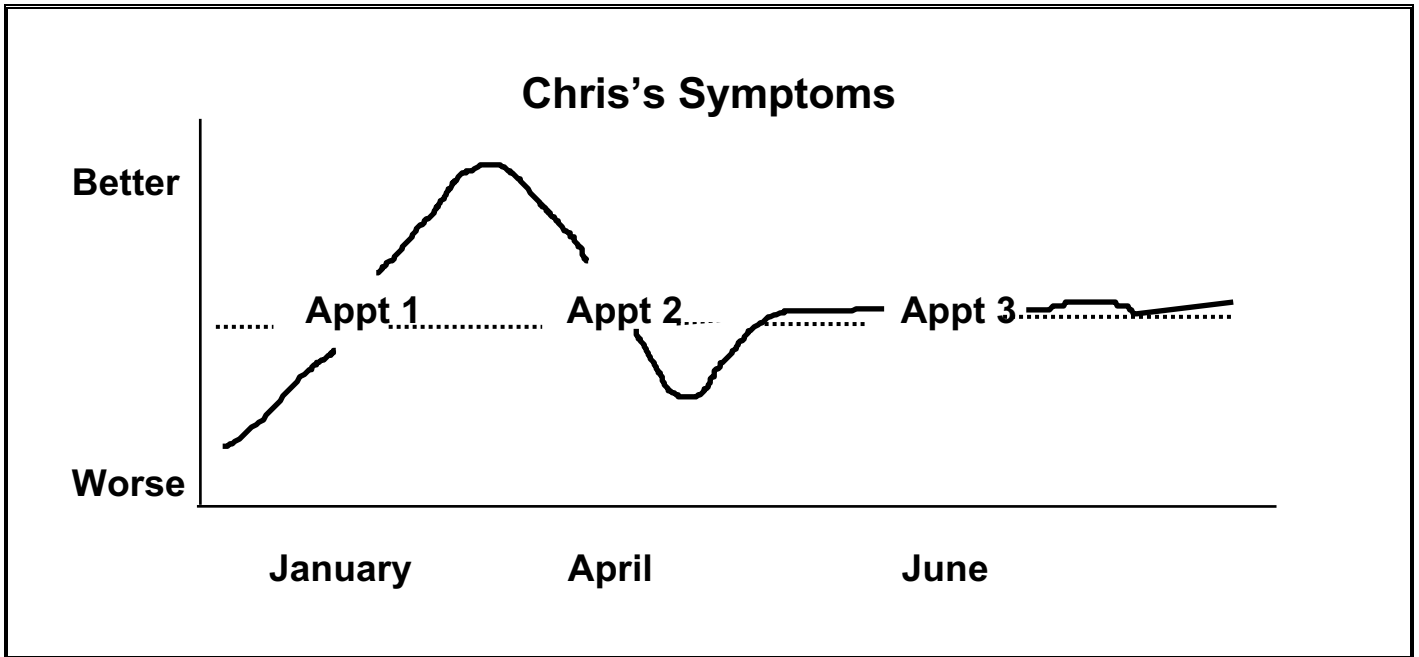


Chart 12

Take P.A.R.T.

- Prepare**
- Ask**
- Repeat**
- Take action**

Chart 13

Do a F.A.S.T. Check

- Fever**
- Altered mental status**
- Severe**
- NOT Typical**

Chart 14

Taking HIV Medications

- 1. Remembering to take them**
- 2. Flexibility to schedule them**
- 3. Fitting into your lifestyle**
- 4. Possible changes to current the therapies**
- 5. Possible side effects**
- 6. Support in place**
- 7. Making it right for you**
- 8. Ready to commit**

Chart 15

Three Kinds of Physical Activities and Goals

- **Flexibility**
Goal: 10 minutes without stopping
- **Strengthening**
Goal: 8-10 strengthening exercises 2-3 days a week
- **Endurance or Aerobic**
Goal: Moderate aerobic activities 30-40 minutes, 3-5 days a week

Chart 16

Communication Skills

1. Identify
2. Express your feelings
 - Use direct “I” messages
 - Use “When this happens...I feel...”
3. Listen attentively
4. Clarify.

Chart 17

The Plate Method

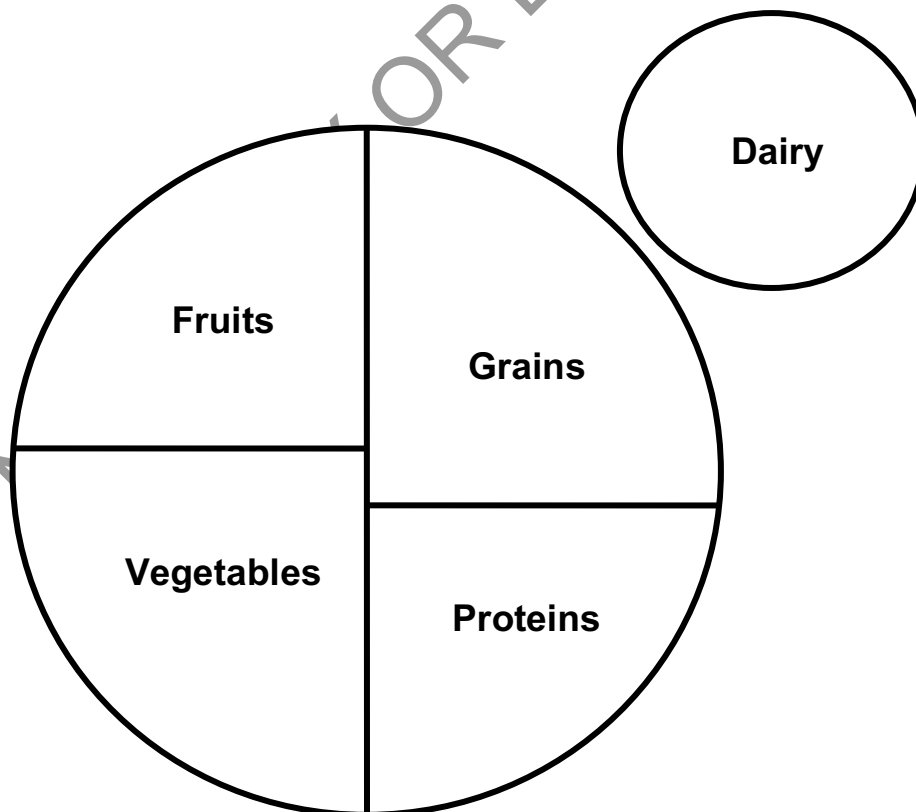


Chart 18

Healthy Eating Guidelines

- 1. Work toward 5 portions of fruit and/or vegetables a day**
- 2. Choose foods lower in fat**
- 3. Limit foods that can raise cholesterol**
- 4. Watch carbohydrates**
- 5. Reduce the amount of salt or sodium**
- 6. Maintain a healthy weight**
- 7. Use safe food preparation methods**

Chart 19

Advance Directives

- 1. Decide on and express your wishes**
- 2. Discuss with your family and your agent**
- 3. Discuss with your doctors**
- 4. Sign the document and have it witnessed**
- 5. Keep in appropriate places**

Chart 20

Steps Toward Positive Thinking

- 1. Write down self-defeating thoughts**
- 2. Change them to rational and helpful thoughts**
- 3. Rehearse**
- 4. Practice**
- 5. Be patient**

Chart 21

Maintaining a Healthy Weight

- 1. Pay attention to portion size**
- 2. Use the plate method of choosing foods**
- 3. Limit foods with more than 5 grams of fat per**
- 4. Eat 5-7 portions of fruit and vegetables a day**
- 5. Drink water or broth-based soups**
- 6. Plan your meals and snacks and plan for regular eating times**
- 7. Eat breakfast**

Agendas should be posted each session, either as a pre-made chart or on a part of the board that is not erased until the end of the session. Agendas help with time management.

Session One Agenda

- Activity 1: Introduction to Workshop (20 minutes)
- Activity 2: Group Introductions (30 minutes)
- BREAK (20 minutes)
- Activity 3: The Mind-Body Connection/Distraction (20 minutes)
- Activity 4: Monitoring HIV (10 minutes)
- Activity 5: Introduction to Action Plans (40 minutes)
- Activity 6: Closing (10 minutes)

Session Two Agenda

- Activity 1: Feedback/Problem-Solving (30 minutes)
- Activity 2: Managing Fatigue (15 minutes)
- Activity 3: Making Decisions (20 minutes)
- BREAK (20 minutes)
- Activity 4: Dealing with Difficult Emotions (40 minutes)
- Activity 5: Making an Action Plan (20 minutes)
- Activity 6: Closing (5 minutes)

Session Three Agenda

Activity 1: Feedback (25 minutes)

Activity 2: Informing Your Healthcare Team (20 minutes)

Activity 3: Taking HIV Medication (20 minutes)

BREAK (20 minutes)

Activity 4: Problem-Solving (30 minutes)

Activity 5: Better Breathing and Relaxation Body Scan (15 minutes)

Activity 6: Making an Action Plan (15 minutes)

Activity 7: Closing (5 minutes)

Session Four Agenda

Activity 1: Feedback (20 minutes)

Activity 2: Dealing with Depression (15 minutes)

Activity 3: Physical Activity & Exercise (25 minutes)

BREAK (20 minutes)

Activity 4: Sex, Intimacy & Telling Others (20 minutes)

Activity 5: Communication Skills (25 minutes)

Activity 6: Making an Action Plan (20 minutes)

Activity 7: Closing (5 minutes)

Session Five Agenda

Activity 1: Feedback (20 minutes)

Activity 2: Healthy Eating (20 minutes)

Activity 3: Getting a Good Night's Sleep (10 minutes)

BREAK (20 minutes)

Activity 4: Future Planning and Legal Issues (20 minutes)

Activity 5: Positive Thinking (25 minutes)

Activity 6: Making an Action Plan (20 minutes)

Activity 7: Closing (5 minutes)

Session Six Agenda

Activity 1: Feedback (20 minutes)

Activity 2: Working with Your Health Care Provider and Health Care System (25 minutes)

Activity 3: Weight Management (20 minutes)

BREAK (15 minutes)

Activity 4: Building Support Systems (20 minutes)

Activity 5: Looking Back and Planning for the Future (40 minutes)

Activity 6: Closing (5 minutes)

Workshop Overview and Homework Handout

The Workshop Overview handout should be photocopied for your workshop participants. This is the **ONLY** handout for the participants.

The homework assignments on the page following the overview may be copied on the back of the Workshop Overview.

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Workshop Overview

	Week1	Week2	Week3	Week4	Week5	Week6
Overview of self-management and long term health conditions	●					
Using your mind to manage symptoms	●		●		●	
Monitoring HIV	●					
Making an action plan	●	●	●	●	●	
Feedback on action plan		●	●	●	●	●
Problem-solving		●	●			
Managing fatigue		●				
Making decisions		●				
Dealing with difficult emotions		●				
Working with your healthcare team			●			●
HIV Medications			●			
Better breathing			●			
Relaxation body scan			●			
Dealing with depression				●		
Physical activity & exercise				●		
Sex, intimacy & telling others				●		
Communication skills				●		
Healthy eating					●	
Getting a good night's sleep					●	
Future planning & legal issues					●	
Positive thinking					●	
Weight management						●
Building support systems						●
Accomplishments						●

Suggested Homework by Session

Session 1:

- Reading covered this session: *Living a Healthy Life with HIV*, Chapters 1 and 2, pages 88-90, 171-172, 175-178.
- Practice using distraction.
- In Session 2, we will be talking about making decisions. Please think of something in your life for which you need to make a decision and have it ready for next week's activity.

Session 2:

- Reading covered this session: *Living a Healthy Life with HIV*, pages 22-24, 138-140, 152-164
- You may want to keep a journal of your feelings.

Session 3:

- Reading covered this session: : *Living a Healthy Life with HIV*, Chapters 6, 8 9, 10, pages 136, 146-148, 172-176
- Start a medication log and symptom diary

Session 4:

- Reading covered this session: *Living a Healthy Life with HIV*, Chapters 5, 13, 16, pages 7-9, 47-50, 53, 57-58, 152-157
- Consider starting an exercise program
- **In Session 5, we will look at what we eat for at least 2 days during this week.**
 - We suggest using one day during the week and one day on the weekend because our eating habits are often different on the weekends.
 - During Healthy Eating, we will share what we learned if we want to make changes in our physical activity program and/or eating habits. The information about what we eat will be useful when we talk about healthy eating next week.

Session 5:

- Reading covered this session: *Living a Healthy Life with HIV*, Chapter 14, pages 148-152, 178-180, 276-283, 315-322
- Be aware of negative thoughts and practice changing them to positive, helpful thoughts
- Call, email or write a letter to your provider about what you have accomplished during this workshop. If you are not pleased with your progress over the past 6 weeks, we would like you to write a letter to the developers of this workshop explaining your reasons. The address is: Self-Management Resource Center • PO Box 219 • Aptos CA 95001 USA • smrc@selfmanagementresource.com. You don't have to mail or show these letters, if you don't want to, but please bring them with you next week for your own use in the sharing activity. If you do mail the letter to your provider, though, it would really help to get the word out about the program.

Session 6:

- Reading covered this session: *Living a Healthy Life with HIV*, Chapters 6, 18, pages 238-240

APPENDIX II: ACTION PLAN AND FEEDBACK FLOW CHARTS

The following flow charts are designed to help the Leader make decisions on how to help a participant make an Action Plan or problem-solve barriers either during the Action Plan or Feedback activities.

It can help in two ways:

1. The Leader can use the charts to prepare for the Action Plan and Feedback activities
2. The Co-Leader can follow the chart while the Leader facilitating is working with a participant, reminding him/her if something is missed

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Making an Action Plan Flow Chart

One Leader stands at Chart 5, pointing to “What”

What is your Action Plan for this week?

Doesn't want to do one

OK, but if you change your mind, we'll check back with you when everyone has shared theirs, or you can catch me or *[name of other Leader]* after class.

Move on

Shares plan

Leader points to “How much” and waits for participant to answer question - then does the same for “When”
“How often”
“Confidence level”

Plan is clear and confidence level is 7+

Thank you! We look forward to hearing about how it went next week.

Move on

Doesn't know what he/she would like to do
OR
Parts are missing or unclear
OR
Low confidence level

Go to next page to continue flow chart

Making an Action Plan Flow Chart (continued from previous page)

Plan is clear, but confidence level less than 7

One Leader points to "Confidence" on Chart 5

Your confidence level is under 7, which tells us that you are unsure that you can complete your plan. What is it that makes you unsure?

What do you think you could do to your plan that would make you more sure?

[prompt if nothing is offered:]

Could less time or fewer days help you feel more sure?

Participant has adjusted plan

Great! Could you please restate your plan, starting with "I will"?

Move on

Participant doesn't have ideas

Would you like some ideas from the group?

NO

We need to go to the next person. *[Name of other Leader]* and I will be available at break or after class, if you'd like more help.

Move on

YES

Brainstorm ideas from the group, asking person to keep track of ideas

Ask if any of the ideas were helpful, ask to restate plan, starting with "I will".

Move on

Doesn't know what to do, parts missing or unclear

Go to next page to continue flow chart

Making an Action Plan Flow Chart (continued from previous page)

Plan is unclear, missing parts, or participant doesn't know what he she wants to do

The more specific the plan, the greater chance of success!

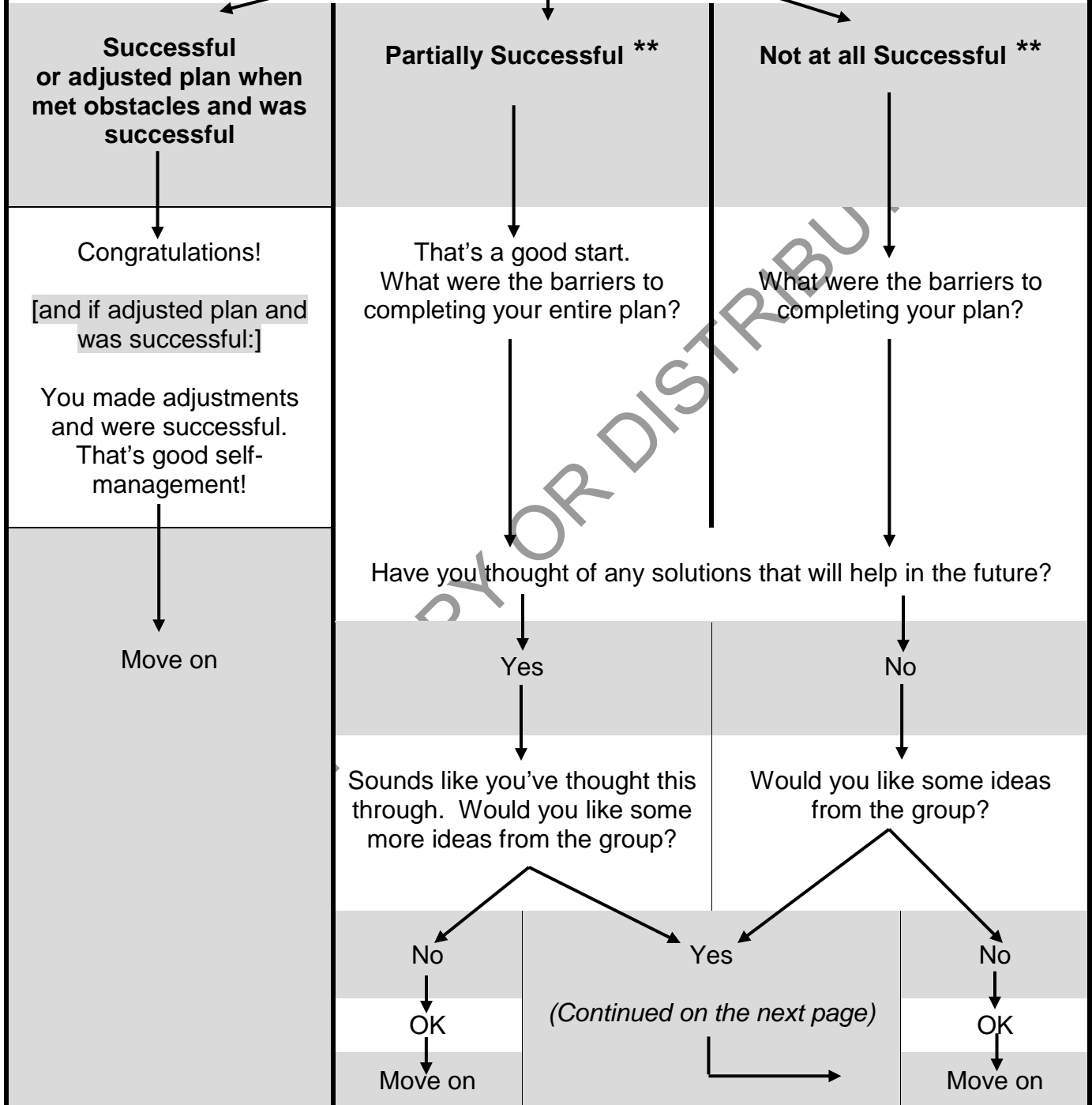
Leader points to each section of the plan on Chart 5 while discussing these

Doesn't know what to do	<u>"What"</u> is not clear	<u>"How much"</u> is not clear or missing	<u>"When"</u> is not clear or missing	<u>"How often"</u> is not clear or missing
<p>Would you like to listen to other plans and have us come back to you?</p> <p>[OR]</p> <p>Would you like to think about it some more? If you need help, you can catch us after class.</p>	<ul style="list-style-type: none"> Is it an action, or the result of an action? For example, losing weight is not an action. Is it something that can be measured? 	<ul style="list-style-type: none"> This is amount of time, distance, volume, number of repetitions, etc. 	<ul style="list-style-type: none"> This is which days of the week, times of the day Commonly mixed up with "how often" 	<ul style="list-style-type: none"> How many days this week? This is a number, not days of the week
<p>↓</p> <p>Move on</p>	<p>Once clarified, ask them to repeat the plan, starting with "I will".</p>			

Remember – 3 “yes buts” and they’re out!

Feedback Flow Chart

What was your Action Plan and how did it go?



Feedback Flow Chart (continued from previous page)

Conduct a brainstorm. Write suggestions on board or chartpad or just ask the participant to keep track, depending on time.

After the brainstorm,
ask original participant if any of the ideas will help

No

You'll have a chance to make an Action Plan every week. Think about what you would like to do next time.

If anyone thinks of any more ideas, catch _____ at break or after class.

Move on

Yes

Which did you find helpful?

We look forward to hearing about your Action Plan next time.

Move on

**** If someone is partially successful or not successful because of being sick or other reasons out of their control**

Sometimes life gets in the way. You need to take care of yourself.

Don't forget, though, that you can adjust or completely change your Action Plan at any time.

Remember – 3 “yes buts” and they’re out!

APPENDIX III: “PROBLEM ACTION PLAN / FEEDBACK EXAMPLES

Please see the Action Plan and Feedback flow charts in Appendix II for guidance. This appendix gives you some concrete examples of not-perfect Action Plans and Action Plan Feedback.

Remember:

- “What” = Specific action (e.g., walking, replacing junk food snacks with fruit)
- “How much” = Time, distance, amount, etc., (e.g., 30 minutes, 5 blocks, 5 repetitions, 1 glass, 1 serving)
- “When” = Time of days or days of the week (e.g., after dinner, Monday and Wednesday)
- “How often” = Number of times in the week (avoiding “every day”)
- “Confidence level” = from “0” being not at all sure to “10” being totally sure (of completing the entire plan)

Action Plans

Doesn't Know What to Do

Leader: What is your Action Plan this week?

Participant: I don't know. What do you think I should do?

Leader (pointing to chart): This is **your** Action Plan, and it can be about anything. Is there something you would **like** to do?

Participant: Well, I can't really think of anything right now.

Leader: Would you like to have some time to think about it, or listen to other Action Plans first? Maybe you will get some ideas as you listen to others. We'll come back to you.

Co-Leader should make sure that the facilitating Leader remembers to come back to that person after everyone else has shared, then:

Leader: Did you think of something you would like to do this week?

Participant: Not yet.

Leader: That's OK, if you think of something during the week, you can make an

Action Plan with yourself then. We can also help you a little more after class today, if you'd like.

And again, at the end of the session:

Leader: Have you decided on something you would like to do this week?

Participant: No

Leader: That is OK, you will have another chance next week.

Doesn't Want to Make a Plan

Leader: What is your Action Plan this week?

Participant: I don't want to do an Action Plan.

Leader: That's OK. If you change your mind after you hear some others, please let us know.

Leader moves on to the next participant. The person should be invited again to make a plan next week.

And again, at the end of the session:

Leader: Have you decided on something you would like to do this week?

Participant: No

Leader: That is OK, you will have another chance next week.

Makes Plan for Every Day

Note: If the Action Plan is for taking medication, do not intervene if someone says they are going to do it 7 days. Just accept it.

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will work in my garden

How much: a half-hour

When: before dinner

How often: every day

Confidence: 9

Leader: Good plan, and you really seem confident. Please think about whether or

not you want to make the plan for every day, though. If something comes up one of those days and you don't get to your plan that day, it may be disappointing to you. On the other hand, if you make your plan for 3 days and do it for 6, you've exceeded your plan! Success is the important thing here. Would you like to adjust your plan to fewer than every day?

Participant: That's a good idea. I'll change it to 4 days.

Leader: Great! Could you please tell us your new Action Plan?

Leader points to each item on the chart as participant restates plan.

Or, alternately:

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will work in my garden

How much: a half-hour

When: before dinner

How often: every day

Confidence: 9

Leader: Good plan, and you really seem confident. Please think about whether or not you want to make the plan for every day, though. If something comes up one of those days and you don't get to your plan that day, it may be disappointing to you. On the other hand, if you make your plan for 3 days and do it for 6, you've exceeded your plan! Success is the important thing here. Would you like to adjust your plan to fewer than every day?

Participant: No. I want to do this every day.

Leader: Terrific. Let us know next week how it goes.

Hedges on Plan

This can happen frequently and is often subtle. Leaders need to listen carefully for cues like "if it rains", "If I feel well", "If I don't have to work overtime", etc.

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will walk

How much: 4 blocks

When: after dinner, Tuesday, Thursday, Saturday, Sunday

How often: 4 days, unless it rains

Confidence: 7

Leader: Good plan, with a good confidence level. I noticed that you added “unless it rains”. Good self-managers have back-up plans ready so they can be successful if something comes up. How could you change or add to your plan to cover yourself if it rains? We want you to be successful!

Participant: OK, if it rains, I’ll do 20 minutes on my Wii exercise program instead.

Leader: Great! We look forward to hearing about it next week.

Plan Depends on Another Person

This can come up often, where the participant wants to exercise with his/her spouse or friend, do a social event with someone else, visit with someone, etc.

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will go to a movie with my friend

How much: 1 movie

When: when we are both free

How often: once

Confidence: 8

Leader: Spending time with people we care about is a good Action Plan, and your confidence level is high. Making Action Plans that depend on other people can be risky, though. It’s usually better to make a plan that depends only on you. You can’t always know if someone else will want to or be able to do what you plan. If you do not know for sure that your friend wants to go, could you make a backup plan, just in case?

Participant: Well, that’s a good point. I’m not sure.

Leader: It sounds like this is something you really want to do. Would you like to make a backup plan?

Participant: That’s a good idea. I need to think of one, though.

Leader: We’ll continue around the room while you’re thinking. We’ll come back to you.

Co-Leader should make sure that the facilitating Leader remembers to come back to that person after everyone else has shared.

Plan Seems Like Too Much to Leader

Generally, Leaders should rely on the confidence level to determine whether or not to probe the participant about their plan. However, if the plan seems like too much for the person to you, other participants are probably thinking the same thing, so addressing it may be appropriate.

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will bicycle

How much: 50 miles

When: Saturday and Sunday mornings

How often: 2 days

Confidence: 10

Leader: You have a good confidence level, which is great! How many miles to you bicycle now?

Participant: I haven't done it for a while.

Leader: When was the last time you bicycled 50 miles?

Participant: I used to do it before I got sick, so it's been at least a year.

Leader: It's your plan and your decision, but we'd urge you to think about this plan. Perhaps reading up on getting back into an exercise program in your book might help, or talking with your health care provider since you haven't done this level of exercise since you got sick. Your confidence level is high, though! Do you want to keep this plan, or would you like to do a different plan?

Participant: I want to keep it for now.

Leader: OK, but remember you can adjust it or even change it to something entirely different during the week, if you'd like.

Plan Isn't an Action

This is another common error that participants make. The two most common are "losing weight" and "getting to sleep". "Losing weight" is the result of an action, such as "replacing cookie with an apple", "drinking a glass of water before eating", or "avoiding 2 snacks". "Getting to sleep" is the result of an action, such as "going to bed an hour earlier" or "listening to a relaxation exercise at bedtime".

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I go to sleep earlier
How much: 1 hour
When: Monday through Friday, 10:00 pm
How often: 5 days
Confidence: 8

Leader (pointing to “action specific” on chart): Getting more sleep is a good idea for many of us, and you have a good confidence level. But sleep is actually the result of actions, rather than an action itself. What is it that you are going to do to help you get an hour more of sleep?

Participant: I will go to bed earlier.

Leader: OK, that makes sense. Could you tell us your Action Plan again?

Leader points to each item on the chart as participant restates plan.

Low Confidence Level

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will clean my desk
How much: 30 minutes
When: before dinner, Saturday and Sunday
How often: 2 days
Confidence: 5

Leader (pointing to “confidence” on chart): Your plan is very specific, but you don't seem to be sure about being able to complete it. We have found that a confidence level of 7 or better usually means that the plan will be completed, and you have a 5. What do you think is preventing you from feeling confident about completing your plan?

Participant: I don't have a routine on weekends, so I forget.

Leader: What might help you remember?

Participant: I just forget.

Leader: Would you like some ideas from the group?

Participant: Yes, that would be nice.

Leaders start problem-solving process. After 5 suggestions:

Leader: Good ideas, everyone! Is there an idea on this list that will help you with your plan?

Participant: Yes. Setting the alarm on my phone might work.

Leader (pointing to the chart): Great! Could you please tell us your Action Plan again?

Leader points to each item on the chart as participant restates plan.

Confuses “How Much” and “How Often”

Leader: What is your Action Plan this week?

Participant (while Leader is pointing to each point on the chart):

What: I will walk to the farmer’s market

How much: Once

When: Saturday morning

How often: Once

Confidence: 7

Leader (pointing to “How much” on chart): That sounds like a pleasant way to increase physical activity. “Once” is the correct response for “how often”, but when we ask “how much”, though, we want to know something like distance or time. Can you tell us either how far you will walk or how many minutes it will take?

Participant: Oh, I see. It’s 7 blocks from my house to the market, so it would be 14 blocks to and from.

Leader: Good. Can you please tell us your Action Plan again?

Leader points to each item on the chart as participant restates plan.

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Didn't Do It At All

Leader: What was your Action Plan last week and how did it go?

Participant: I was supposed to keep a food diary 3 days, but I didn't do it.

Leader: What was it that prevented you from doing your plan?

Participant: I didn't really have time. I ate out a lot last week because of my work schedule.

Leader: Have you thought of any ideas about what you would do if this were to happen again?

Participant: No. I haven't really thought about it.

Leader: Would you like some help from the group?

Participant: Sure.

Leader: We'll get 4-5 ideas from the group. Does anyone have some suggestions on what to do if you don't have time to do a food diary?

(Leader gets up to 5 ideas from the group, then asks original participant if any of them are helpful)

Didn't Do It At All – Didn't Like it

Leader: What was your Action Plan last week and how did it go?

Participant: I was supposed to keep a food diary 3 days, but I didn't do it.

Leader: What was it that prevented you from doing your plan?

Participant: I didn't really have time. I ate out a lot last week because of my work schedule. I know it's something I need to do, but I don't like doing it.

Leader (pointing to "Something you want to do" on the chart): It sounds like keeping a food diary isn't something you really want to do. It's important to do something we **want** to do while we're learning how to do Action Plans.

Participant: Yes, but my diabetes educator says I need to do this.

Leader: Your Action Plan is something you choose to do, so if you want to keep this Action Plan in the future, that's your decision. Have you thought of any ideas that would help you keep your food diary in the future?

Participant: Not really.

Leader: Would you like some help from the group?

Participant: Sure.

Leader: We'll get 4-5 ideas from the group. Does anyone have some suggestions on what to do if you don't have time to do a food diary and don't really like doing it?

(Leader gets up to 5 ideas from the group, then asks original participant if any of them are helpful)

OR, another way:

Leader: What was your Action Plan last week and how did it go?

Participant: I was supposed to keep a food diary 3 days, but I didn't do it.

Leader: What was it that prevented you from doing your plan?

Participant: I didn't really have time. I ate out a lot last week because of my work schedule. I know it's something I need to do, but I don't like doing it.

Leader (pointing to "Something you want to do" on the chart): It sounds like keeping a food diary isn't something you really want to do. It's important to do something we **want** to do while we're learning how to do Action Plans.

Participant: Yes, but my diabetes educator says I need to do this.

Leader: Your Action Plan is something you choose to do, so if you want to keep this Action Plan in the future, that's your decision. You will have another chance this week, so think about something you really want to do. An Action Plan is for you and not for anyone else.

Partially Complete – Unhappy About It

Leader: What was your Action Plan last week and how did it go?

Participant: My Action Plan was to ride my exercycle for 30 minutes, 5 days. I only did it 4 days, so I failed.

Leader: So, you got 4 days of physical activity - that's a great start! What was it that prevented you from doing it on the 5th day?

Participant: My sister and her kids came to visit, and there was just too much going on.

Leader: It's not unusual for things to come up that we weren't expecting. Would you like help from the group about this?

Participant: No, that's OK. I think visiting with my sister was important.

Leader: Yes, visiting family can be very good for us! I think you should be happy with your progress. You got off to a great start with your physical activity goal. Remember, you can always adapt your Action Plan when things come up. Having a back up plan can also be helpful.

Partially Complete – OK With It

Leader: What was your Action Plan last week and how did it go?

Participant: My Action Plan was to ride my exercycle for 30 minutes, 5 days. I did it 4 days, so I got most of it done. My sister and her kids came to visit, and I was too busy with them to do the fifth day.

Leader: So, you got 4 days of physical activity - that's a great start! Would you like to problem-solve about the 5th day with the group, or are you OK with how it turned out?

Participant: No, thanks. I'm happy that I got 4 days done, and happy with my decision to spend that time with my family.

Leader: Yes, visiting family can be very good for us! You got off to a great start with your physical activity goal. Remember, you can always adapt your Action Plan when things come up. Having a back up plan can also be helpful.

Partially Complete – Too Ambitious

Leader: What was your Action Plan last week and how did it go?

Participant: My Action Plan was to ride my exercycle for 30 minutes, 7 days. I did it 5 days.

Leader: Five days is a good start towards being more physically active. What stopped you from doing your exercise 2 more days?

Participant: It was just too much. I should not have said I'd do it every day.

Leader: Yes, we recommend that people not make their plans for every day. Things come up, and it can be difficult to work without any wiggle room. Would you like to problem-solve with the group?

Participant: No, I've learned my lesson! I won't plan something for every day in the future.

Partially or Not Complete – Got Sick

Leader: What was your Action Plan last week and how did it go?

Participant: I said I would walk 4 days, but I was sick all last week and couldn't do it.

Leader: I'm glad you're feeling better and could join us today. It's important that we use common sense and take care of ourselves when we are sick. That's good self-management. Remember, though, you can change your Action Plan at any time. Having a backup plan to do something to take care of yourself when you are sick could be a good Action Plan!

Adjusted or Changed Plan

Leader: What was your Action Plan last week and how did it go?

Participant: My plan was to walk 4 day, but I was sick all week. I changed my plan to testing my blood sugar 4 times each day for 5 days, and I was able to do that.

Leader: Congratulations on completing your new plan! That was great self-management! Good self-managers change or adjust their Action Plans when something prevents them from doing their original plan.

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APPENDIX IV: DEALING WITH DIFFERENT TYPES OF PEOPLE / SITUATIONS

The following descriptions of different types of people and potentially difficult situations are presented here to stimulate your thinking about how **you** might handle these effectively during a workshop you are facilitating. Being prepared ahead of time may even help you prevent such problems. Each situation is different; therefore, use your best judgment to determine what suggestions might be effective in real situations.

If a difficult situation persists, discuss it with your co-Leader, the program coordinator and/or Master Trainers. Together, you will get the support you need and can decide how best to handle the problem.

People

The Too-Talkative Person

This is a person who talks all the time and tends to monopolize the workshop.

The following suggestions may help:

- Remind the person that we want to provide an opportunity for everyone to participate equally.
- Refocus summarizing the relevant point, then move on.
- Spend time listening to the person outside the group.
- Assign a buddy. Give the person someone else to talk to.
- Use body language. Don't look toward the person when you ask a question. You may even consider having your back toward the person.
- Talk with the person privately and praise him/her for contributions; ask for help in getting others more involved.
- Thank the person for the good comment and tell him/her that you want everyone to have a turn at answering the question.
- Say that you won't call on someone twice until everyone has had a chance to speak once first.

The Silent Person

This is a person who does not speak in sharing activities or does not become involved in activities.

The following suggestions may help:

- Watch carefully for any signs (e.g., body language) that the person wants to participate, especially during group activities like brainstorming and problem-solving. Call on this person first, but only if he/she volunteers by raising a hand, nodding, etc.
- Be sure the person participates in the Action Planning and Feedback activities.
- Talk to them at the break and find out how they feel about the workshop.
- Respect the wishes of the person who really doesn't want to talk; this doesn't mean that they are not getting something from the class.

The "Yes, but . . ." Person

This is the person who agrees with ideas in principle but goes on to point out, repeatedly, how it will not work for him/her.

The following suggestions may help:

- Acknowledge participants' concerns or situation.
- Open up to the group.
- After three "Yes, but's" from the person, state the need to move on and offer to talk to the person later.
- It may be that the person's problem is too complicated to deal with in the group, or the real problem has not been identified. Therefore, offer to talk to the person after the session and move on with the activity.
- If the person is interrupting the discussion or problem-solving with "Yes, but's," remind the person that right now we are only trying to generate ideas. Ask him/her to please listen and later we can discuss the ideas if there is time. If there is no time, again offer to talk to the person during the break or after the session.

The Non-Participant

This is the person who does not do his/her homework (i.e., reading, Action Plans, exercise, relaxation, etc.)

The following suggestions may help:

- Recognize that the people taking the workshop are more variable than their chronic conditions. Some may not be ready to do more than just listen. Others may already be doing a lot, or are overwhelmed, especially if newly diagnosed. Some may be frightened to get "too involved." Still others may be trying their homework, but do not want to talk about it in the group. Whatever the reason, do not assume the person is not benefiting from the workshop in some way, especially if he/she is attending each session.
- Do not spend extra time trying to get this person to participate.
- Continue to state that homework is designed to help participants adjust to the disease process and to make life more manageable. The Action Plans should be something the participant wants to do. Do not assign or prescribe Action Plans for any participant.
- Congratulate those participants who do the assignments.
- Encourage those who do the assignments to share what benefits they have obtained.
- Realize that not everything will appeal to everyone in the same way or at the same time.
- Do not evaluate yourself as a Leader based on one person who chooses not to complete assignments or to participate in activities. If no one is doing the assignments or participating, however, it may be that the Leaders are not modeling well themselves.

The Argumentative Person

This is the person who disagrees, is constantly negative and undermines the group. He/she may be normally good natured but upset about something.

The following suggestions may help:

- Keep your own temper firmly in check. Do not let the group get excited.
- If in doubt, clarify your intent.
- Call on someone else to contribute.

- Have a private conversation with the person, ask his/her opinion about how the workshop is going and whether or not he/she has any suggestions or comments.
- Ask for the source of information, or for the person to share a reference with the group.
- Tell the person that you'll discuss it further after the session if he/she is interested.
- State that this workshop has been evaluated and reviewed by national and local committees of different medical professionals, and that you are to follow the approved manual.
- Offer to contact your sponsoring organization (hospital or other) to discuss the issue.
- Suggest that this person write their suggestions or comments to the Self-Management Resource Center at PO Box 219, Aptos CA 95001 USA, smrc@selfmanagementresource.com, or the national or local coordinator of your program at _____

The Angry or Hostile Person

You will know one when you see one. The anger most likely has nothing to do with the Leader, group or anyone in the group. However, the Leader and groups members are usually adversely affected by this person and can become the target for hostility.

The following suggestions may help:

- Do not get angry yourself. Fighting fire with fire will only escalate the situation.
- Get on the same physical level as the person, preferably sitting down.
- Use a low, quiet voice.
- Validate the participant's perceptions, interpretations, and/or emotions where you can.
- Encourage some ventilation to make sure you understand the person's position. Try to listen attentively and paraphrase the person's comments in these instances.
- If the angry person attacks another participant, stop the behavior immediately by saying something like, "There is no place for that kind of behavior in this group. We want to respect each other and provide mutual support in this class."
- When no solution seems acceptable ask, "At this time, what would you like us to do?" or "What would make you happy?" If this does not disarm the person,

suggest that this class may not be appropriate for him/her.

The Questioner

This is the person who asks a lot of questions, some of which may be irrelevant and designed to stump the Leader.

The following suggestions may help:

- Don't bluff if you don't know the answer. Say, "I don't know, but I'll find out."
- Redirect to the group: "That's an interesting question. Who in the group would like to respond?"
- Touch/move physically close and offer to discuss further later.
- When you have repeated questions, say, "You have lots of good questions that we don't have time to address during this session. Why don't you look up the answer and report back to us next week." (This could even be an Action Plan for the coming week.)
- Suggest that the answer can be found in the book.
- Deflect back to topic.

The Know-It-All

This is the person who constantly interrupts to add an answer, comment, or opinion. Sometimes this person actually knows a lot about the topic and has useful things to contribute. Others, however, like to share their pet theories, irrelevant personal experiences and alternative treatments, eating up class time.

The following suggestions may help:

- Restate the problem.
- Limit contributions by not calling on the person.
- Establish the guidelines at the start of the session and remind participants, when appropriate, that information about alternative treatments will not be discussed in this workshop. Rather, we will be discussing some guidelines for evaluating such treatments later in Session 4.
- Thank the person for positive comments.
- If the problem persists, invoke the rule of debate: Each member has a right to speak twice on an issue but cannot make the second comment as long as any

other member of the group has not spoken and desires to speak.

The Chatterbox

This is a person who carries on side conversations, argues points with the person next to him/her or just talks all the time about personal topics. This type of person can be annoying and distracting.

The following suggestions may help:

- Stop all proceedings silently waiting for group to come to order.
- Stand beside the person while you go on with workshop activities.
- Arrange the seating so a Leader is sitting on either side of the person.
- Restate the activity to bring the person back to the task at hand or say, "Let me repeat the question."
- Ask the person to please be quiet.

The Crying Person

Occasionally, a group discussion may stimulate someone in the group to express their feelings of depression, loss, sorrow or frustration by crying. People cry for many reasons. They may feel that someone finally understands what it's been like, which makes them feel safe to express emotions they have been suppressing for a while. Crying is usually a release that promotes emotional healing. To allow a person to cry is helpful; it may also help to bring the group closer together providing mutual support to one another. Your role is to convey that is okay to cry, so the person does not feel embarrassed in front of the group.

The following suggestions may help:

- Always have a box of tissues handy and pass it to the person.
- Acknowledge that it is all right to cry — having a chronic condition is difficult, then continue on with the class.
- If the person is crying a lot, one Leader may want to accompany the person out of the class to see if anything needs to be done. The other Leader should continue on with the rest of the group.
- Generally, if no one tries to stop the crying, within a short period of time, it will play itself out. Tension will be released, and the person will feel better and the participants will feel closer to the person.

- At the break or after the session, ask if the person is okay now and if he/she needs help with anything. Reinforce to the person that crying is a perfectly normal, healthy behavior, and that he/she is not the first to cry in this class. In fact, it has happened quite often and probably will in the future.

The Suicidal Person

Rarely, you may encounter someone who is very depressed and is threatening to take his/her own life or expresses severe hopelessness or despair.

The following suggestions may help:

- Remember your own limits and know in advance a crisis intervention resource to which you can immediately refer the person.
- Talk to the person privately. One Leader can accompany the person out of the room and urge him/her to get help. This Leader may also provide the person with the names, phone numbers and/or addresses of some specific resources in the community that can help.
- Contact your program coordinator immediately. He/she will need to follow up with the person.

The Abusive Person

This is someone who verbally attacks or judges another group member.

The following suggestions may help:

- Remind the group that all are here to support one another.
- Establish a group rule and remind everyone that each person is entitled to an opinion. One may disagree with an idea someone has but under no circumstances will personal attack be appropriate. If the abuse continues ask the person to leave.

The Superior Observer

This is a person with a superior attitude who says he/she is present out of curiosity, and that he/she already knows everything about the chronic disease and coping well.

The following suggestions may help:

- If the person indeed does know a lot and is coping well, you may consider approaching him/her about taking the Leader training after finishing the workshop.
- If the person knows a lot but is not doing well, you may point out the difference between knowledge and behavior. This workshop is designed to encourage the incorporation of self-management practices in one's life.
- A person may also act superior if he/she feels uncomfortable and not a part of the group. If so, include him/her in some way.
- If the person wants to be ignored, then ignore them. They will get bored and leave or start to participate.

The Person Who Doesn't Make Action Plans

This is a person who continues to make vague commitments in making an Action Plan or won't make a commitment.

The following suggestions may help:

- If the person is adamant, they he/she does not want to make a plan, don't try to engage him/her, just move on to the next person. Ask again next week.
- Ask him/her about what problems or difficulties he/she is having related to chronic disease. Ask them to identify the first step they would take to make a change. Break down the goal to a very specific step.
- Tell the person you will come back to him/her after everyone else has shared a goal. After hearing the others, he/she may be able to state one.
- If the person refuses to make a commitment, talk with him/her during a break or before or after the meeting and ask him/her about it. If you can identify why the person won't, you can probably help him/her through the resistance or difficulty. As facilitators of this workshop, however, we cannot make anyone do anything if he/she does not want to do it.
- Move on to the next person. Don't give this person too much extra attention when others in the group are ready to participate.

The Person in Crisis

The person in "crisis" is the one with the problems, who wants help and/or just needs to talk about these problems.

The following suggestions may help:

- Listen attentively, be empathetic, use open-ended questions, use reflective listening.
- If after five minutes it is obvious that the person will need more time to "unload," talk to person during the break or afterwards, as you will have to go on with the workshop activities.
- Don't take up session time and energy with the very "needy" person because it takes time away from the other participants who can be helped.

Situations

In-class Practices

How can you get everyone to participate in relaxation and other activities during the session?

The following suggestions may help:

- Make sure that everyone understands instructions.
- Review BENEFITS of activities.
- Set up the expectation that we will do these together.
- State that we want everyone to participate according to what they are able to do.
- Observers can make others uncomfortable.
- If someone doesn't participate on several occasions or activities, ask him/her about it during the break and if there is any way you can help.
- Most people will participate if you set the expectation. Say, "We will now do _____. Do not say, "If you like you can _____." Occasionally you might encounter someone who will not. If you find that more than an occasional person doesn't participate, you may consider how you are asking the group to participate, and whether or not you as Leaders are modeling appropriately.
- If someone is uncomfortable with relaxation techniques, he/she may resist closing eyes and/or uncrossing his/her arms or legs. Don't push the person to conform. Perhaps with time after hearing how much other group members like

it, the person will relax more.

Creating a Non-Threatening Atmosphere

How can you facilitate a warm, relaxed and friendly atmosphere that encourages sharing?

The following suggestions may help:

- Be prepared and greet people when they arrive. If you wish, offer beverages or provide snacks.
- Arrange the chairs in a circle so everyone can see each other.
- Smile or use humor.
- Address people by name and use name tags so everyone can learn each other's names.
- Do a relaxation technique yourself before the session starts so that you as a Leader are relaxed. Be prepared to facilitate.
- Structure sharing by telling the group that each person will have a chance to respond. Give people time to answer before moving on, even if there are 30 seconds of silence.

Handling Questions

How do you handle questions when you don't know the answer?

The following suggestions may help:

- If you do not know the answer, it is appropriate to say "I don't know."
- You can ask your co-Leader and the group if they know the answer, but only if it is reasonable to expect that they will know the answer. Do not do this for medical questions.
- Suggest that the group refer to the book, *Living a Healthy Life*, or other resource material (if available), for the answer.
- No one is expected to know everything, plus knowing everything would be impossible.

Co-Leader Illness

What to do if you or your co-Leader is too ill to come to the workshop?

Tips:

- Recruit a substitute (must be a trained Leader).
- If you are facilitating with only one other person and cannot get a substitute, you may want to postpone the session if there is time to reach the participants and put a notice on the door of the room announcing the cancellation.
- You may have a contingency plan for the beginning and schedule the room for an eight-week period, "just in case." This may be especially useful if there are only two Leaders or if you will be facilitating during possibly severe winter weather, storms, tornadoes, etc.
- If you feel able and well enough prepared to facilitate the session by yourself, explain to the participants why the other Leader is not present.

Support of Physicians

What to do if an angry health care provider calls about his/her patient's activities in the workshop:

Tips:

- Listen and find out what the health care provider is angry about. It may or may not be something you did in the workshop.
- Depending on the reason, you may invite the physician to look at the workshop materials to see what is included or invite him/her to observe or attend (in a non-medical role) the workshop.
- You may tell him/her that the workshop was approved by the _____ committee of your organization.
- You may tell him/her about the evaluation results or send him/her a copy of them.
- Inform the program coordinator about the call.

Relaxation Interruptions

What to do if the phone rings or someone knocks at the door while you're in the middle of a relaxation exercise?

Tips:

- The best way to deal with this is prevention. Place a note on the door stating that a relaxation exercise is in progress, and please do not disturb.
- Unplug the phone or ask the switchboard to hold calls. Also, ask participants to turn off pagers, beeping watches and cellular phones.
- One of the Leaders can handle the interruption, unless he/she is deeply relaxed and does not respond.
- Can incorporate this into the script, for example, say "Continue to relax and breathe slowly and deeply while I answer the phone/door, and I will be right back to you."

Running Out of Time

It's important to always end your meetings at the scheduled time out of respect to your members. However, if you are continually having to end meetings without finishing your business, then examine how well you are managing your time.

The following suggestions may help:

- Show by example that you are aware of the time. Wear a watch; start and end on time.
- Review the agenda or post it. Inform the group about time allotments and ask for their cooperation.
- Prepare all materials, flipcharts and equipment ahead of time, rather than during the meeting.
- Work with a co-Leader and have your co-Leader signal with a "T" sign when it's time to move on.
- If already behind, tighten up only the presentation. Set time limits on participants' questions or opinions, cover key points of lectures and tell the group to refer to the book for more information.

Other Attendees

Spouses, significant others, family members, etc., are encouraged to accompany the person who has a chronic disease to the workshop. They are registered members of the class. These people should participate in the workshop as active members, i.e., they don't just sit and watch.

Make it clear that it is important that they attend each session. Group size is limited, so if a spouse, significant other, family member, etc., signs up to attend and then doesn't attend regularly, they have taken the place of another person who could have benefited from the workshop.

Injury Control

What would you do if a group member sustains an injury during your workshop?

Tips:

- As a preventative measure, know where a telephone is, and know the number to call (e.g. 911, extension for emergency room if in a hospital, etc.)
- The first priority would be to get the level of help needed to the person as fast as possible and to provide comfort to the injured while you were waiting for help to arrive.
- How you would react depends on the severity of the injury. If the injury is major, you most likely would not continue with the session. If the injury is minor, the co-Leader can continue with the session, once help was obtained.
- Once the co-Leader sees that the injured person is being taken care of, he/she can refocus on the needs of the rest of the group.
- If an accident occurs, be sure to inform the program coordinator after the immediate needs are handled.
- It is helpful to write a summary of what happened and provide it to the program coordinator.
- Remember, it is better to be proactive. Ensure that chairs, etc., are arranged for easy access and that access ways are clear (i.e., keep floors clear of cords, loose rugs and clutter)

APPENDIX V: TRAINING TECHNIQUES USED IN THE WORKSHOP

Lecturette

A short oral presentation in which the Leader(s)/ Facilitator(s) present facts, principles or explanations about a topic. It is used most often in this workshop to provide information or explain briefly the basic concepts covered in the workshop.

Utilizing the basics

- Explain the purpose of the lecturette to the group.
- Motivate the group by relating the lecturette to the questions or problems that have been raised in the group.
- Cover only those points of the topic that are presented on the charts, and only use the additional information provided in the *Leader's Manual* to elaborate briefly on the topic. This helps the Leader manage the time more effectively as well as to maintain the interest of the participants.
- Do not read material word by word to the participants from the *Leader's Manual* or directly out of the book, *Living a Healthy Life*.
- Focus your attention on individuals in the group.

Advantages of using the lecturette:

- Allows the Leader to cover a lot of material in a short period of time.
- Leaders can be fully prepared ahead of time.
- Provides information that may be difficult for participants to find quickly on their own.
- Material can be presented concisely and in an orderly manner, so that it is easily understood by the participants.

Points to note:

- Participants may lose interest if the lecturette is not well prepared or well delivered.
- Participants may become too passive just listening and not contributing to the group process.
- Participants may not remember and/or understand the content.

Brainstorming



Brainstorming is a freewheeling technique to generate ideas. The group is given a question or problem and asked to produce as many ideas as possible through a creative, spontaneous flow of suggestions with no comment, judgment or evaluation of the suggestions given.

Free association is encouraged, and ideas are written exactly as they are called out. Quantity is more important than the quality of the ideas offered. After all the suggestions are given, a more careful analysis of the ideas, clarification and/or explanation can be done.

Procedure

- The facilitator reads the question as written in the manual.
- The scribe writes the brainstorm question, using KEY words.
- The facilitator repeats the ideas loudly, using the participant's own KEY words while looking at group, not at the scribe.
- If the idea is too long, the participant to shorten it. If they cannot, ask for permission from them if you shorten or rephrase it.
- The scribe listens only to the co-Leader and writes what the facilitator says.
- The scribe does not use abbreviations or symbols.
- The scribe is responsible for telling the facilitator if they can't keep up with the ideas.
- The facilitator controls the "traffic"- slowing the brainstorm if the scribe needs to catch up.
- Neither the facilitator nor the scribe comment or allow anyone else to comment on the ideas (positively or negatively, verbally or by facial expression).
- The facilitator does not allow questions until after the brainstorm is over.
- If there are less than 15 ideas, the facilitator uses silence **...W...A...I...T...!** (it's not over until you have counted to 15 to yourself with no new ideas). If there are no more, the brainstorm is over.
- The facilitator does NOT call on people.
- The scribe tells the facilitator when there are 15 ideas listed.
- If there are 15 ideas, the facilitator tells the group you will take 2 more and end the brainstorm.

- After the brainstorm, the scribe or facilitator reads back the list to the group.
- the facilitator asked if any ideas need clarification.
- If there are ideas listed in the manual to add, the facilitator adds only those ideas that are not already listed.
- If any ideas are “inappropriate”, such as alcohol or violence, the facilitator points this out politely without pointing anyone out.

Call Outs

Call outs are used to involve the group by having them call out the answer to questions posed by the Leader (facilitator), taking less time than in a brainstorm. Responses are not written down.



Procedure

- One Leader (facilitator) asks the question, e.g., “How many servings or listed on this food label?”
- The facilitator looks at the group until the correct answer is called out
- The facilitator repeats the correct answer to the group, e.g., “Yes, it says 2 serving on this package label”
- The facilitator quickly moves on

Demonstration/Practice

Participants observe the Leaders performing a task that demonstrates what something is and how to do it. After the demonstration, the participants then practice the task. Demonstration and practice are used to make the explanation of a skill or technique more concrete for the participants.

Utilizing the basics

- Explain the purpose of the skill or technique and tell the participants what details of the demonstration they should notice.
- Keep the directions simple, using words that the participants can understand.
- Briefly demonstrate the skill or technique.
- Involve participants in the demonstration by having them practice the skill.
- Check that each participant can perform the skill correctly. To be effective,

participants should not just watch, but also do the skill.

- Summarize or review briefly the key points of the demonstration/practice after it has concluded.
- If someone is having difficulty during the practice, work with them during break or after the session so as not to exceed the time allotted for the activity.

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Appendix VI: Example “What If” Scenarios

Scenario: Action Plan Parts Missing

This week I will exercise three days.

Answer: “Great start, but let’s be more specific! Pointing to the chart, ask: What exercise are you going to do, how long will you do it, and on which days? Even having a specific time can be helpful.”

Scenario: I’m Already Doing Everything

I am already doing everything and don’t want to make an Action Plan.

Answer: “That is your choice. If you think about something you want to do during the week you can just make a plan with yourself.”

Scenario: I Failed

Someone says they failed because they exercised only 3 days instead of 4.

Answer:

- First, praise them for getting started and ask if there was a problem and if they want help.
- If they agree, proceed with problem-solving.

Scenario: “Dangerous” Plan

Jerry, who is overweight and also has diabetes, makes an Action Plan to eat a ½ pint of butterscotch ice cream after dinner 4 nights and has a confidence level of 9.

Answer:

- Resist the temptation to comment. Treat it as any other Action Plan that has all the correct points and a good confidence level.
- Don't be judgmental. It's possible that he normally eats a pint of ice cream 6 nights a week!

Scenario: Awful Week

During Feedback, Tonya says that she did not do her action plan because she had a migraine all week. Her grandson broke his leg, her cat died, her husband came home drunk and broke up the house. To top things off, she does not have anything in the house to eat.

Answer:

- "Tonya, it sounds like you had lots of problems I understand why you could not do your Action Plan. Let's talk during break." Then continue with the others in the group.
- Tanya is a person in crisis. This is probably real but may also be a way of trying to focus the group on her. Problem solving would just bring about more problems and suck the group into an ever-deepening black hole.
- You can talk with Tonya during break and see if anything can be done. However, by focusing the workshop on Tanya you are harming the other 11 people, one of whom may be silently coping with a dying husband and financial problems.

Scenario: Perpetually Partially Complete

It is Session Four, and Jamal reports that he has partially completed his Action Plan. This has happened every session. You have worked with him when making a plan to make it achievable, and problem-solved when he was not completing successfully every week.

Answer:

- If this is a pattern from the beginning, there's not much the Leaders can do when Session 4 comes around.
- Do as you would with any other partially complete plan: problem-solve, if he wants to do so.
- Do not get caught up with someone who doesn't "get" the Action Plan concepts in later sessions. It will eat up time that can be spent on participants who do "get" Action Planning.

Scenario: "Just Trying to Help..." Brainstorming

During a brainstorm, someone asks questions or makes comments about some of the ideas.

Answer:

- Remind them that they need to wait until after the brainstorm for clarification.
- Point to the Brainstorming chart to reinforce the rules.

Scenario: Yakity-Yak

During Group Introductions in Session One, Betty introduces herself:

"Hi, I'm Betty and I had other health problems before I got HIV. As a child I had polio and that kept me out of school for two years. Now I have post-polio syndrome, so I'm in pain all the time. I also have arthritis. I have had a lot of surgery and am bionic with new shoulders, knees, hips and three fingers. Recently I have had heart problems, but I am on a special diet where I only eat carbohydrates and my cholesterol is going down. I really want to teach all of you

about this diet and also about all the exercises I am doing. I have so many problems I do not know where to start. To begin with my medicine cost 500 dollars a month so I do not have enough to eat. Besides I have to sleep sitting up and am always exhausted. It is hard for me to get the grocery story to get the food I need.”

Answer: The Leader facilitating this activity should cut in after the first or second sentences and redirect by saying something like: “It sounds like you have lots to say but could you just tell us one or two problems living with HIV causes you?”

Scenario: Dead Silence

You call out a question to the group and you wait for a minute, but no one speaks up.

Answer:

- Repeat the question.
- Count to 15 to yourself while looking at the group.
- If there is still silence, give an example of your own to start things.

Scenario: Leader and Participant Know Each Other

As the participants arrive for the first session you recognize one of the participants, as you have known each other from working together in the past.

Answer:

- Emphasize the “Maintain Confidentiality” item on the Guidelines chart during Activity 1.
- Let the participant take the lead on whether or not to acknowledge that they recognize you.
- If you feel comfortable and confident then smile and acknowledge.
- If the participant seems uncomfortable, ask your co-Leader to talk to them privately to ask if they would rather attend another workshop.

Scenario: Explicit Sexual Behavior Discussed

One of your participants repeatedly diverts the activities to discuss in detail their own sexual behavior to the seeming distress of the other participants.

Answer:

- Do not draw attention to the specific individual, however remind the whole group of the activity they have been asked to do
- Remind the group about the guidelines: respecting others
- If the behavior persists, talk to the person outside of the group. “Some people in the group may not be comfortable hearing about your sexual life. Please be respectful to them and refrain from discussing it so frequently.”

Scenario: Offensive Language

Some of your participants are used to using what other participants might consider offensive words.

Answer:

- If you are in a group where this language is the norm, do nothing. Allow them to communicate the way they wish.
- If your group contains some participants who may be offended (which you can probably determine by their body language), remind the whole group about the guidelines: respecting others, and that some may be offended, and different language should be used.
- If the behavior persists, continue reminding them of the guidelines.
- If this happens during a brainstorm, either write the term used, or replace some of the letters with symbols or dashes, i.e., “F - - k”.

Scenario: Ventriloquist

During Group Introductions in Session One, there is a couple sitting together. When you reach the first person, the partner speaks for them, including reporting the problems caused by HIV. The first partner sits quietly.

Answer:

- As soon as the partner starts, stop them.
- Nicely, say: “Thank you _____ but we really would like to hear each person introduce themselves.”
- Looking at the quiet partner would invite them to introduce himself.
- Do not let this dynamic get started! Stop it in the first session.

Scenario: Preaching Exercise

During the Introduction to Physical Activity and Exercise activity’s brainstorm, Bertha blurts out: “I think this exercise stuff is over-done, and it’s being preached everywhere. My Dad and Mom never did any exercise at all and lived to be in their 90s.”

Answer:

- Remind her that we don’t ask questions or make comments during a brainstorm, pointing to the Brainstorming chart. Tell her that she can ask for clarification after all the ideas are out.
- Continue the brainstorm.
- If she repeats her comment when you ask if anyone needs clarification, you can say: “Sounds like your parents were very lucky. There is a great deal of science about the importance of exercise but like any other part of self-management it is your decision as to what you do.”

Scenario: Interpreting Emotions

During the reporting back part of Dealing with Difficult Emotions, Jonathan, reporting for his partner, says: "I think Jack is still grieving over the loss of his son."

Answer:

- Jonathan made a judgmental statement and we want to stop judgments as soon as they happen
- Say to the participant doing the reporting something like: "Jonathan, that sounds like your interpretation of what Jack said. Would you please just tell us what Jack said and not add your interpretation?"
- It is always important to stop judgmental statements made by one person in the group about another.

Scenario: Body Scan Hurts

After the Body Scan, a person says: "This body scan makes my pain worse".

Answer:

- "I'm sorry to hear that. There are other relaxation scripts on your CD. Maybe you will like one of those better."
- You don't have to use all of the tools in the Tool Box, just choose those that work best for you.

Scenario: **Shady Salesman**

Your co-Leader is facilitating the Evaluating Treatments activity, and you overhear one of the participants trying to sell something to another participant.

Answer:

- Go over to the salesperson participant and quietly tell them that selling products of any kind is not permitted in the workshop.
- Even if this happens during the break, the salesman should be advised that it is not allowed.
- If the person persists, notify your program coordinator; it is likely that the coordinator will contact the person and notify them that they may not return to class because they were told it was not allowed and did it anyway.

Scenario: **Waterworks**

During the Making Decisions exercise, while reporting on their decision, a participant starts to cry.

Answer: Acknowledge that making decisions is sometime hard, sometimes sad, and sometime brings relief. Say that:

- It is perfectly OK to have real emotions.
- Hand the person a tissue.
- Then go on.
- If necessary, one of the Leaders can leave the room with the person.

Scenario: **Trust My Gut?**

While facilitating the Making Decisions activity, someone shouts: “What do you mean my gut is more important than the facts?! Facts are facts!”

Answer:

- Facts don't always tell the whole story for many people. This is just a way for someone to check their decision. It helps sort things out for them.

Scenario: Shooting Down Suggestions

“Leader” says: Keisha, you said that you were having a problem communicating your needs to your children. The group has come up with a list of suggestions. Are there any of these you would like to try?

“Participant” says: Well, let me see. I can't just use “I” messages, they would never understand, sending an email seems much too impersonal and I am not sure they would read it. I could name the things I need but none of them has time to help.

Answer:

- “Sounds like this can't be solved right now. We can talk about it more during break or after the workshop.”
- You would say this because you have just heard three ‘yes buts’ and our rule of thumb is three ‘yes buts’ and you are out.

Scenario: Feeling Blue

After the depression activity, a participant says that they has many of the symptoms mentioned and wants to know if you think they are depressed.

Answer:

- “I am not an expert in this area. I would suggest that you talk this over with your health care provider.”

Scenario: Endless Challenging Questions

In the first two sessions Bob questions everything. He challenges you with “What evidence do we have for these exercises? Wouldn't tai chi be better? Isn't cognitive behavioral therapy the best way to treat depression?”

Answer: Several things may be going on.

- Bob may be feeling insecure and in need of being the expert and being in control.
- He may really want to know the answers.

- Have some trusted person in the community introduce you and your co-Leader
- Keep it short and never bluff.
- Above all do not get caught up in a never-ending string of questions which are not of general interest to the group and will just get you off track.
- "I don't have answers to your question (s). During break I can help you with some ideas of where you can find the answer.
- "That is a good question to ask your provider or you may search the answer on your own at the library or on the internet"
- Privately you may say that the information given in this program was obtained from experts like doctors, nutritionists, psychologists, etc.

Scenario: Angry and She Will Tell You Why

Maria came in to the first session angry and things did not get any better that day. She complained about parking and that the room was too hot. She moved her chair out of the circle so she was behind other people. During the introduction she said that she was there because her doctor made her come. Her Action Plan was that during the week she would decide if she would come back.

Answers:

- Acknowledge that parking is difficult and tell her that there is little you can do as you are getting the space for free.
- Do not comment on her introduction and treat her Action Plan like any other Action Plan.
- Talk to her privately during break or after the workshop letting her know how much you welcome her and hope she will return.

Scenario: Touchy-Feely Psycho-Babble

During the Positive Thinking activity, Joe is sitting with his arms crossed and glaring at you. Finally, he says, “This is psycho-babble – touchy-feely stuff. It’s a crock. You are not being honest with yourself and are lying to yourself”.

Answer:

- Do not get into it with Joe.
- Remind him that: “Not all self-management tools are for everybody, that’s why this workshop gives you many tools to choose from. This may not work for you, but it may for someone else.”

Scenario: Hypoglycemia

You notice that Jamie, who has diabetes, is sweating and seems shaky and out-of-sorts.

Answer:

- These are signs of hypoglycemia (low blood sugar) and can easily happen when a participant is engaged in what is going on and forgets to eat.
- The Leader not presenting should deal with this.
- Ask them if they need something to eat or drink.
- Ask them to check their blood glucose, if they can.
- Ask them if they have something to eat with them (candy, sugar packet, fruit, etc.)
- If not, find a sugar soft drink, candy, sugar packet from the coffee area, etc., for them (ask others in the class or go out and get something)
- **Don’t ignore this.** Left alone, it will get worse.

Scenario: Judgmental Participant

During the Problem-Solving activity, Joanne, reporting for her partner, says, “Jerry’s problem is really a minor one. He says he has trouble asking for help from his family. Doesn’t everyone? (laughing)”

Answer:

- This is both judgmental and belittling.
- Tell Joanne: “Joanne, what may seem like a minor problem to one person may feel like a big problem for someone else. Jerry feels this is a problem. What solutions did he come up with?”
- If you ask Jerry if Joanne’s report is accurate and he says “no”, ask Jerry what solutions he came up with.

Scenario: Diets

During the Weight Management activity, a participant asks, “Is that high-protein Atkins diet good for losing weight?”

Answer:

- Say something like: “We aren’t nutrition experts. In this workshop we talk about general guidelines for healthy eating, so each person decides their eating plan. You might ask your health care provider or ask for a referral to a Registered Dietitian.”

Scenario: Here, Try These...

You see participants sharing and exchanging medication in class or at the break.

Answer:

- Stop it immediately. Tell them it is not allowed.
- Explain that sharing medications is very dangerous. It can cause serious problems.

Scenario: Treatment Advice

During the Medications activity, someone says, “I take a really good homeopathic medication for side effects. I’ll bring it next week so everyone can try it.”

Answer:

- Say something like: “Everyone’s treatment plan is different. Therefore, we don’t allow sharing of treatments or medications in the workshop. Please don’t bring them to class.”
- Suggest that they look in *Living a Healthy Life with HIV* for medication side effects information.
- Remind everyone that if they start an over-the-counter medication or treatment, that’s it important to let their health care provider know about it. Some can interfere with their other medications.

Scenario: Medications are Bad

During medications activity, a participant states that they refuse to start medication and that that a vitamin regimen and alternative therapies work just fine.

Answer:

- Remind the group that starting medication is a personal choice, but any decision should be made in conjunction with your health care professional
- If the participant continues to want to discuss it, suggest that you can continue this conversation in the break.

Scenario: Doctor-Bashing

During the Informing your Healthcare Team activity, someone says, “I have the Better Care HMO, and they denied me a medication because they said there was a cheaper one I could take! Can you imagine? All they care about is money and they’ll do anything to cut their expenses.”

Answer:

- Remind the participant that we don’t want specific health plans or health care professionals named in the workshop.
- Tell them that they should talk to their provider about this. Perhaps he/she could file an appeal.
- Say something like: “If you feel you are being denied something unfairly, you can talk to the patient advocate within the organization. They have different names, depending on the organization, but all HMOs have them.”
- Do not allow the group to get into a discussion on how poor the organization is, etc.

Scenario: Can’t Use “The Plate”

While discussing The Plate Method, in the Healthy Eating activity, Sally says, “I can’t use this plate. I’m lactose intolerant.”

Answer:

- Suggest that she talk to her health care provider about what to use instead of dairy products.
- Suggest that she might ask her doctor for a referral to a Register Dietitian. They are experts in helping people find the right combination of foods.

Scenario: That Costs Too Much

During the Healthy Eating activity, someone says:

“You said we should go to a Registered Dietician, but they cost money. What if we can’t afford it?”

Answer:

- “Talk to your health care provider and tell them your concerns.”
- “Check with your health insurance provider to find out if it’s a covered benefit.”
- If the organization hosting the workshop has a social worker or community services person, tell the person that you can meet during break to help them find some resources.
- Open it up to the group for problem-solving, if you have time.

Scenario: Asking for Doctor Recommendations

During the Working With your Health Care Provider and Health Care System activity, someone says during the problems with their health care provider brainstorm, “I used to have Dr. Brown, but he treated me like a child, so I just switched to Dr. Green. Does anyone else go to Dr. Green?”

Answer:

- Immediately inform them that we don’t allow names and discussion about specific providers during the workshop. If they want to share recommendations, they can talk to each other at break or after class.

Scenario: Expecting Expertise

Someone says, “I have heard that fish oil is good for a lot of things. What do you know about it?”

Answer: “This is a good question to ask your health care provider.”

Scenario: You're late!

Say in your own words: At the second session John arrives a half hour late. Your co-Leader is facilitating and welcomes John and then reminds him that we start on time. What would you do and when?

Answer:

- The Leader should not comment on lateness in front of the whole workshop. Maybe John was in an accident and is already upset.
- The Leader who made the comment should apologize to John during the break. If John is feeling hurt by the remark this will go a long way toward solving the problem. What is important is to keep the participants engaged.
- As a rule of thumb, trainee behavior should usually be discussed in private.
- If the Leader who made the comment does not take the initiative and apologize to John, the Leader that observed this situation should point out to the co-Leader that this remark was out of place. It is best to do damage control early. We all say things without really thinking and if made aware will probably not make the same mistake twice.
- Simply ignore John's lateness
- The Leaders could talk to John during the break to find out the problem and if appropriate remind him that the workshops start on time.

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Scenario: “You Shouldn’t Feel that Way!”

During the difficult emotions’ activity, Susan’s partner reports that Susan says that she feels useless because she can’t do what she used to. Your co-Leader blurts out, “You shouldn’t feel that way.”

Answer:

- Susan’s feelings are hers. Nobody likes to be told how to feel.
- Telling someone that their feelings are “bad” is judgmental.
- Ignore your co-Leader and ask Susan if her partner’s report was correct.
- Thank Susan for sharing something that’s hard to share.
- Go on to the next person.
- Talk privately with your co-Leader about how their expression of concern was not appropriate.
- Using the word “should” is a red flag in this workshop.
- If they argue with you, talk with your program coordinator.

Scenario: Lost

Your co-Leader is facilitating, and you realize that they are stumbling, not following the manual and is generally lost.

Answer:

- If this goes on for more than 30 seconds or a minute, break in nicely and ask you co-Leader if they would like some help. Then do the activity yourself.
- This can happen if one is not really prepared. That’s why both Leaders have to be prepared all the time to do the whole workshop. Be prepared.

Scenario: “Control Freak” Co-Leader

Your co-Leader is treating you like an “assistant” during the workshop, rather than a partner.

Answer:

- Talk to them in private as soon as possible.
- Explain that this is not good modeling for the group and is not consistent with the Stanford model.
- Work out specifics about what they should not do
- Come up with a plan on exactly which one of you will do what.
- If it continues, contact your program coordinator for assistance.

Scenario: Ambitious Co-Leader

Your co-Leader makes an Action Plan for 7 days.

Answer:

- You and your co-Leader should decide on Action Plan details before each workshop. This will give you an opportunity to correct this modeling error before it becomes a problem in class.
- If this happens during the workshop, lead them through the Action Plan steps as you would with any participant, reminding them that we suggest making Action Plans for 3-5 days.
- Remind them that sometimes we are so enthusiastic about our plan and we can forget to allow some room for things that may get in the way.
- Talk to them after class about the importance of good modeling.

Scenario: Missing Co-Leader

It's 5 minutes after the start time for the session, and your co-Leader hasn't arrived. They have the charts and the roster.

Answer:

- Start the session.
- You can read the charts from the manual.
- Get everyone to sign in on a piece of paper and update the roster later.

Scenario: Leader Personality Clash

You don't like your co-Leader, and the feeling seems to be mutual. You can't seem to agree on anything.

Answer:

- If you can stand each other and are able to complete the 6-week workshop without involving the participants in the relationship, tough it out.
- Ask your program coordination to arrange a meeting to clarify the process and protocols that need to happen even if the Leaders don't like each other.
- Be specific about what you don't like.
- Tell you program coordinator that you do not want to be paired with this person again.

Scenario: Co-Leader Goofs Up and then Blows Up

Your co-Leader misses a section of the activity, and you step in when there is an opportunity to cover it. After the participants leave, your co-Leader goes ballistic on you, saying that you should be quiet during any activity she is doing.

Answer:

- Explain that it's most important that the program is delivered as designed and that all content be delivered to the participants.
- Tell your co-Leader that you hope that they would step in if you missed something.
- If you don't think this has resolved the program, arrange a meeting with the program coordinator.

Scenario: Poor Demonstration

During the Better Breathing activity, your co-Leader demonstrates diaphragmatic breathing incorrectly.

Answer:

- Tell the group: "Sometimes this is difficult to explain. Let me add to what you just saw."

Scenario: Cultural Humility #1

You have been asked to facilitate a workshop where most of the participants will not be of your racial or cultural group. The same is true of your co-Leader. At the first session, only half the participants have arrived, but you start on time. The others trickle in over the next hour. You also notice that there are long silences during the brainstorm and not much participation. By the end of the session several participants are sitting with their arms crossed. What could you have done to make this first session easier?

Answer: Things the Leaders could have done:

- Talked to several people in the community before the workshop to find out about community norms
- Have some trusted person in the community introduce you and your co-Leader
- You might even say to the participants that this has felt uncomfortable and ask them what you can do next week to make things better

Scenario: Cultural Humility #2

You are giving a workshop at a Jewish community center, although most of the participants are not Jewish. The workshop starts at 1:00 PM, so a participant asks if they can bring their lunch. You say this would be fine but that they cannot bring meat or seafood. They says that they is free to eat anything they want and you have no right to tell them what to eat. What could you have done and what should you do now?

Answer: Things the Leaders could have done:

- If the site you are using has special restrictions, in this case allowing only Kosher food, this should be mentioned when giving the guidelines in Session 1.
- Since not everyone will understand what Kosher means, you can ask someone at the center to come and explain.
- If the situation happened as described above, then one of the Leaders should apologize for not being clearer and then explain that this is a Jewish center that only allows Kosher food. Because most meat products are not Kosher, they have decided that the easy way to deal with this is to allow only fruit, vegetables, dairy products, and fish - no meat or shellfish.

- If the participant still wants to bring meat, then they can eat it outside during the break.

Scenario: Cultural Humility #3

You are not sure of a participant's gender. How do you address the person?

Answer:

- Use the person's name instead of pronouns.
- Avoid using gender specific words like him and her; rather use "they" or "them" or "their".

Scenario: Cultural Humility #4

You have a diverse group with diverse political, cultural, sexual identity, or generational issues. It seems to be negatively impacting the group.

Answer:

- The tone is set by the Leaders. Creating an atmosphere where the participants can contribute freely is important.
- When preparing for the session, revisit your Leader's Manual Appendix IV to ensure that you're familiar with some of the ways to handle difficult people and situations.
- Make sure to allow participants to select partners for the pair-and-share activities.
- Talk with your program coordinator. If the problem is serious, some sort of intervention by a professional might be necessary.

Scenario: Left Outside

Say in your own words: You have a workshop on Saturday, but the door is locked when you arrive.

Answer:

- If you have an after-hours workshop, make sure that your program coordinator has supplied you with directions on who to contact if the room isn't open.
- Visit the site ahead of time during open hours and talk to a site coordinator about what to do in this situation.
- Contact your program coordinator.
- Try to find an open office or security office who might be able to let you in.
- If no one is available to help, try to find somewhere close by that will allow you to meet
- If all else fails, cancel the session

Scenario: Participant Death

Harry's buddy in the workshop calls you between sessions to report that she just learned that Harry has died.

Answer:

- Inform your program coordinator.
- Get a non-religious sympathy card and have those who wish to sign it do so during the next session. Mail the card to the family.
- If there is a memorial service, share the details about the service with the participants.

APPENDIX VII: HOW TO WORK WITH PARTICIPANTS WITH MEMORY ISSUES*

Provided by the Alzheimer's Association

A recent survey of Chronic Disease Self-Management Program (CDSMP) trainers about the relevance of CDSMP for persons with Alzheimer's and other forms of dementia (ADRD) found that these persons and sometimes their care partners or other family members participate in CDSMP workshop in significant numbers. www.umb.edu/gerontologyinstitute/publications/longterm_care/#alzheimers

With 95% of Medicare beneficiaries with Alzheimer's disease or related dementia having at least one other chronic disease (www.alz.org/facts), it is not surprising to see many participants with a cognitive impairment attending CDSMP workshops. As a result, CDSMP Leaders will find participants living with Alzheimer's disease in their workshops who may be challenged by some of the CDSMP workshop activities.

In the survey, trainers reported the adjustments they made to the workshop to accommodate the needs of persons with cognitive impairment while still maintaining fidelity to CDSMP. Often trainers were simply doing more of what is already integral to the program or using an existing recommended optional strategy.

After review of the survey results, Kate Lorig, DrPH, the researcher who developed CDSMP, suggested that the Alzheimer's Association compile a tip sheet based on the survey responses that will provide Leaders with useful ways to accommodate persons with a cognitive impairment. The following are presented to help you make the workshop more effective, maximize program benefits and create an atmosphere that is welcoming for the person with dementia.

When working with participants with Alzheimer's disease or other dementia, the following suggestions may be beneficial:

1. Do more of what is already integral to the program (repetition); consider presenting information at a slower pace and speaking more slowly.

**Although this appendix is about Alzheimer's, we include it because the strategies are applicable for any memory-loss condition.*

2. Allow the person with dementia additional time to respond to questions or report back in group activities.
3. Use optional strategies within the program (such as the buddy system), or pair participants in activities.
4. Consider having another trainer present during breaks or before/after workshop to provide extra detailed explanations of instructions, clarify questions or conduct follow-up phone calls between sessions.
5. Ask the person with dementia what accommodations they may need to be successful; if the care partner is in attendance, they may be able to identify the person's residual strengths and weaknesses.
6. Try to reduce distractions or ask the person to sit in front or near the Leaders; provide more reinforcement (praise, encouragement), set more modest/attainable expectations and ensure action plans are clear, concise and contain achievable goals.
7. When possible, write down step-by-step directions and allow for more note taking and writing as this can be a way for the person with dementia to remember material from the workshop and serve as a memory tool for reminders.
9. Brainstorming may be a difficult process for persons with dementia; plan to repeat the process steps for brainstorming, problem solving, and steps for action planning every time you do any of these activities.
10. Remember to speak directly to the person with dementia even if the care partner attends the workshop with them.
11. Know the 10 Warning Signs of Alzheimer's disease; take the Alzheimer's Association's free online course *Know the 10 Signs- Early Detection Matters* at <http://elearning.alz.org/Default.aspx>.
12. Learn the facts about Alzheimer's disease, take the Alzheimer's Association's free online course *The Basics: Memory Loss, Dementia and Alzheimer's Disease* at www.alz.org/index.asp.
13. Contact the Alzheimer's Association's 24/7 Helpline for additional information and resources at 800-272-3900.

Participants with Care Partners

The survey of CDSMP trainers found that Care Partners attending workshops with a person with dementia (usually a spouse) could be an added resource that increases the benefits of CDSMP and provides some hands-on assistance in the following weights:

- Provides a liaison between the person with dementia and the group Leader
- Assists with the Action Plan process (developing the plan and ensuring follow-through during the week)
- Helps the person with dementia by explaining and reinforcing instructions and information
- Helps the group understand the person's contributions in group activities by clarifying, interpreting, etc.
- Takes notes to facilitate follow through and carry-over between sessions
- Assists in recalling instructions and information presented in the workshops

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APPENDIX VIII: HISTORY OF STANFORD SELF-MANAGEMENT PROGRAMS

1978+ The Arthritis Self-Management Years

In 1978, Kate Lorig came to Stanford to create an arthritis education program. This program was mandated by a grant from The U.S. National Institutes of Health to the newly funded Stanford Multipurpose Arthritis Center, part of Stanford University School of Medicine.

By early 1979, the Arthritis Self-Management Program had been written and the first 14 leaders trained. Over the next year, nearly 300 people attended programs, and by 1980 Kate had completed her doctoral dissertation for University of California Berkeley, *Arthritis Self-Management: A joint Venture*.

→ **This study showed that a small-group, peer-led arthritis program could change health status and health behaviors.**

Publication: Lorig, Kate, et al. "Outcomes of self-help education for patients with arthritis." *Arthritis & Rheumatism* 28.6 (1985): 680-685.

Based on this evidence, the U.S. National Arthritis Foundation disseminated the program nationally and continued to do so into the 21st century.

For the next nearly 30 years, the Stanford Arthritis Center, now names the Stanford Patient Education Research Center, conducted a number of studies of community-based arthritis education programs and established some of the evidence that underlies all of our works today.

The following are some of the key findings from this period and their references.

→ **The Arthritis Self-Management Program reduced costs.**

Publication: Lorig Kate R, Mazonson Peter D, and Holman Halsted R. "Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs." *Arthritis & Rheumatism* 36.4 (1993): 439-446.

→ **Self-Efficacy is one of the factors explaining beneficial outcomes.**

Publications:

Lorig Kate, et al. "The beneficial outcomes of the arthritis self-management workshop are not adequately explained by behavior change." *Arthritis & Rheumatism* 32.1 (1989): 91-95.

O'Leary Ann, et al. "A cognitive-behavioral treatment for rheumatoid arthritis." *Health Psychology* 7.6 (1988): 527.

Lorig Kate, et al. "Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis." *Arthritis & Rheumatism* 32.1 (1989): 37-44.

→ **Reinforcement may not add anything**

Publication: Lorig Kate, and Holman Halsted R. "Long-term outcomes of an arthritis self-management study: Effects of reinforcement efforts." *Social science & medicine* 29.2 (1989): 221-224

→ **Shorter versions of the Arthritis Self-Management Program are not as effective**

Publication: Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

→ **Lack of strong evidence that professionals are better than peers as program leaders.**

Publications:

Cohen Judith L, et al. "Evaluation of arthritis self-management workshops led by laypersons and by professionals." *Arthritis & Rheumatism* 29.3 (1986): 388-393.

Lorig Kate, et al. "Arthritis self-management program variations: Three studies." *Arthritis & Rheumatism* 11.6 (1998): 448-454.

→ **Spanish Speakers benefit from the Spanish Arthritis Self-Management Program**

Publications:

Lorig Kate, González Virginia M, and Ritter Philip. "Community-based Spanish language arthritis education program: a randomized trial." *Medical care* 37.9 (1999): 957-963.

González, Virginia M, et al. "Translation and validation of arthritis outcome

measures into Spanish." *Arthritis & Rheumatism* 38.10 (1995): 1429-1446.

- **People with arthritis have similar benefits if they participate in disease specific (Arthritis Self-Management Program, or generic (Chronic Disease Self-Management) workshops.**

Publication: Lorig Kate, Ritter Philip L, and Plant Kathryn. "A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients." *Arthritis Care & Research* 53.6 (2005): 950-957.

- **A mailed version of the Arthritis Self-management program was successful in English, Spanish and for African Americans who had called and asked for the mail delivered tool kit.**

Publication: Goeppinger Jean, et al. "Mail-delivered arthritis self-management tool kit: A randomized trial and longitudinal followup." *Arthritis Care & Research* 61.7 (2009): 867-875.

- **The Arthritis Self-Management Program leads to sustained (2-year) benefit.**

Publication: Osborne Richard H, et al. "Does self-management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians." *The Journal of Rheumatology* 34.5 (2007): 1112-1117.

- **Arthritis Self-Management can be effective for those 80 and older.**

Publication: Lorig Kate, Laurin Janette, and Holman Halsted R. "Arthritis self-management: a study of the effectiveness of patient education for the elderly." *The Gerontologist* 24.5 (1984): 455-457

- **The Arthritis Self-Management Program can be effective when delivered via the Internet.**

Publication: Lorig Kate R, et al. "The internet-based arthritis self-management program: A one-year randomized trial for patients with arthritis or fibromyalgia." *Arthritis Care & Research* 59.7 (2008): 1009-1017.

1990+ The Chronic Disease Self-Management Years

In the early 1990s we developed and studied the Chronic Disease Self-Management Program. Early studies were funded by California state tobacco money and the Agency for Health Care Policy and Research. This study was conducted in conjunction with Kaiser Permanente. We found that treatment participants when compared to randomized controls increased healthful behaviors, improved health status and had less health care utilization.

- ➔ Publication: Lorig K, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, González VM, Laurent DD, Holman HR. “Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial”. *Medical Care* 1999; 37(1):5-14
- ➔ Publication: Lorig K, Ritter P, Stewart A, Sobel D, Brown BW, Bandura A, González VM, Laurent DD, Holman H: “2-year evidence that chronic disease self-management education has sustained health and utilization benefits”. *Medical Care* 2001;39(11):1217-1223.

The original CDSMP study was followed up by a longitudinal study that included several Kaiser Permanente regions. This study had findings similar to the original study.

- ➔ Publication: Lorig KR, Sobel D, Ritter PL, Hobbs M, Laurent D. “Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice* 2001;4:256-262.
- ➔ Publication: Sobel DS, Lorig KR, Hobbs M. “Chronic condition self-management program: from development to dissemination”. *Permanente Journal* 2002;6(2):11-8.

As part of the U.S. Recovery Act, a second large translation study included 22 sites in the United States. Again, the findings were similar to the original study.

- ➔ Publication: Ahn S, Basu R, Smith ML, Jiang L, Lorig K, Whitelaw N, Ory MG. “The impact of chronic disease self-management programs: healthcare savings through a community-based intervention”. *BMC Public Health*: 13(1):114,2013 Dec.
- ➔ Publication: Ory MG, Ahn S, Jiang L, Smith ML, Ritter PL, Whitelaw N, Lorig KL. “Successes of a national study of the chronic disease self-management

program: Meeting the triple aim of health care reform”. *Medical Care*: 51(11):992-8, 2013 Nov

→ Publication: Ory MG, Ahn SN, Jiang L, Lorig K, Ritter P, Laurent DL, Whitelaw N, Smith ML: *National Study of Chronic Disease Self-Management: Six Month Outcome Findings*. *Journal of Aging Health*: 2013,25:1258

There were several other key studies showing the effectiveness of the CDSMP outcomes and cost savings in England.

→ Publication: Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A.” The effectiveness and cost effectiveness of a national lay-led self-care support programme for patients with long-term conditions: A pragmatic randomised controlled trial”. *Journal of Epidemiology and Community Health* 2007;61(3),254-61

→ Publication: Richardson G, Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Gardner C, Gately C and Rogers A. “Cost Effectiveness of the Expert Patients Programme (EPP) for Patients with Chronic Conditions”. *Journal of Epidemiology and Community Health* 2008; 62:361-367.

Effectiveness as an on-line program (Better Choices Better Health)

→ Publication: Lorig KR, Ritter PL, Dost A, Plant K, Laurent DD, McNeil I. “The expert patient programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions”. *Chronic Illness* 2008;4(4):247-256.

→ Publication: Lorig K, Ritter PL, Laurent DD, Plant K. “Internet-based chronic disease self-management: A randomized trial”. *Medical Care* 2006;44(11):964-971.

→ Publication: Lorig k, Ritter PL, Plant K, Laurent DD, Kelly P, Rowe S. “The South Australia Health chronic disease self-management internet trial”. *Health Education and Behavior* 2013 Feb;40(1):67-77.

Effectiveness for people with severe mental health problems

→ Publication: Lorig K, Ritter PL, Pifer C, Werner P. “Effectiveness of the chronic disease self-management program for persons with a serious mental illness: A translation study”. *Community Mental Health Journal* 06/2013 (ePub).

Effectiveness of the CDSMP for people with Diabetes

- Publication: Lorig K, Ritter P, Jacquez A. "Outcomes of border health Spanish/English chronic disease self-management programs". *Diabetes Educator* 2005;31(3):401-409.
- Publication: Lorig, Kate, et al. "Effectiveness of a Generic Chronic Disease Self-Management Program for People With Type 2 Diabetes A Translation Study." *Diabetes Educator* 39.5 (2013): 655-663.

Effectiveness of the CDSMP as a program delivered through the mail

- Publication: Lorig K, Ritter PL, Moreland C, Laurent DD. "Can a box of mailed materials achieve the triple aims of health care? The Mailed Chronic Disease Self-Management Tool Kit study". *Health Promotion Practice: ePub* 2015 Feb 17.

Effectiveness of the CDSMP for people with Depression

- Publication: Ritter PL, Ory MG, Laurent DD, Lorig K. "Effects of chronic disease self-management programs for participants with higher depression scores: secondary analyses of an on-line and a small-group program". *Translational Behavioral Medicine*: 4(4):398-406

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1994+ The HIV Self-Management Years

In response to the HIV/AIDS crisis, the CDSMP was adapted for use in people who were HIV positive. This was done in conjunction with Allen Gifford MD, who at the time was a Robert Wood Johnson Clinical Scholar at Stanford. There have been several trials of both the original program as well as a program revised in the mid 2000s. Since that time, mainly because of new drugs, the face of HIV has changed to look more like other chronic conditions. Thus, the workshop was revised again and released in early 2016.

- Publication: Gifford AL, Laurent DD, González VM, Chesney MA, Lorig KR. “Pilot randomized trial of education to improve self-management skills of men with symptomatic HIV/AIDS”. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology* 1998: 18(2):136-144
- Publication: Gifford AL, Groessl EJ. “Chronic Disease Self-Management and Adherence to HIV Medications”. *Journal of Acquired Immune Deficiency Syndromes* 2002: 31:S163–S166.
- Publication: Webel AR. “Testing a peer-based symptom management intervention for women living with HIV/AIDS”. *AIDS Care* 2010 Sep;(9):1029-40.

1995+ The Chronic Pain Self-Management Years

In the mid-1990s, Dr. Sandra LeFort in St. John’s Newfoundland adapted the ASMP for use by people with chronic pain. The workshop has been used for many years in Canada and more recently in Denmark. In 2015, the workshop was completely revised, and a book was written to accompany the workshop. It was released for public use in mid 2015. It is hoped that a Spanish translation of this workshop will be available in 2016.

- Publication: LeFort S, Gray-Donald K, Rowat KM, Jeans ME. “Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain”. *Pain* 1998;74,297-306
- Publication: Mehlsen M, Heegaard L, Frostholm L. “A prospective evaluation of the Chronic Pain Self-Management Programme in a Danish population of chronic pain patients”. *Patient Education and Counseling* 2015;(5)677-680.

2004+ The Diabetes Self-Management Years

Of the most common chronic conditions, diabetes, is the most behaviorally complex. For this reason, we decided to explore the possibilities of using a community-based self-management program to assist with the growing problem of type II diabetes. Funding for these studies came from the National Institute of Nursing Research, the Archstone Foundation and the National Institute for Diabetes and Kidney Disease. We were assisted by many members of both the American Diabetes Association and the American Association of Diabetes Educators. There are 3 diabetes programs, Spanish (the first program developed), English, an adapted translation of the Spanish program, and Better Choices Better Health, the online diabetes program. All of these programs have been shown to lower A1C and improve health behaviors and health status.

- Publication: Lorig K, Ritter PL, Villa F, Piette JD. “Spanish diabetes self-management with and without automated telephone reinforcement”. *Diabetes Care* 2008;31(3):408-14
- Publication: Lorig K, Ritter PL, Villa FJ, Armas J. “Community-based peer-led diabetes self-management: A randomized trial”. *The Diabetes Educator* 2009 July-August;35(4):641-51.
- Publication: Lorig K, Ritter PL, Laurent DD, Plant K, Green M, Jernigan VBB, Case S. “Online diabetes self-management program: A randomized study”. *Diabetes Care* 2010;33(6):1275-1281

2010+ The Building Better Caregivers Years

In approximately 2010, the U.S. Veterans Administration approached us about developing and evaluating an online program for the caregivers of veterans who suffered from traumatic brain injury, post-traumatic stress disorder, or other cognitive problems. The result was the online Building Better Caregivers, which underwent a small study and is currently used by the V.A. caregiving program, as well as other organizations in the United States.

In 2013 we received a grant from the Archstone Foundation to adapt the online BBC to small face-to-face group format. This trial will come to an end in 2016, after which we hope to release the small group program for general community use.

- Publication: Lorig K, Thompson-Gallagher D, Traylor L, Ritter PL, Laurent DL,

Plant K, Thompson LW, Hahn TJ. "Building Better Caregivers: A pilot online support workshop for family caregivers of cognitively impaired adults". *Journal of Applied Gerontology* June 2012;31(3):423-437

2012+ The Cancer Thriving and Surviving Years

In the early 1990's the Macmillan Trust (a cancer charity in the United Kingdom), adapted the CDSMP for use with cancer survivors. In addition, Dr. Lorig is a cancer survivor and her personal experience led to an interest in this topic. These two factors came together when Stanford was asked by the University of Hawaii to develop an online program for cancer survivors and to assist with its evaluation. This collaboration resulted in Cancer Thriving and Surviving.

In 2012, a second collaboration was formed between Cancer Centers in Colorado, Virginia and Texas, as well as the Stanford Patient Education Research Center. This collaboration developed and studied a small group, face-to-face version of online Cancer Thriving and Surviving. This was released for public use in 2015.

Publication: Bantum EO, Albright CL, White KK, Berenberg JL, Layi G, Ritter PL, Laurent D, Plant K, Lorig K. "Surviving and thriving with cancer using a web-based health behavior change intervention: Randomized controlled trial". *Journal of Medical Internet Research* 2014 Feb;16(2): e54

Publication: Risendal BC, Dwyer A, Seidel RW, Lorig K, Coombs L, Ory MG. "Meeting the challenge of cancer survivorship in public health: results from the evaluation of the chronic disease self-management program for cancer survivors". *Psycho-Oncology*. 2015 Apr 10 (ePub). doi: 10.1002/pon.3783.

APPENDIX IX: PSMP SUGGESTED REVISION FORM

Your Name: _____ Date: _____

Organization name and address: _____

Please describe below your suggestions for a deletion, addition or change in the Positive Self-Management Program content and/or methodology. If your proposed change would replace an existing workshop activity, specify the session and activity number. Use the back of this sheet and/or additional paper as needed.

Please describe the reason for suggesting this change:

Please complete one sheet for each suggested change and submit to:

Self-Management Resource Center
PO Box 219
Aptos CA 95001 USA
smrc@selfmanagementresource.com