

Positive Living



Name: _____

Positive Living

Welcome to “Positive Living”. This is a workbook designed to be used over 6 weeks which aims to help people develop self-management skills for living with HIV/AIDS. Using this workbook is not about sitting and reading or listening. In order to get the most out of this course you will be asked to share your experiences, you will need to set goals and share those goals with others and you will need to take part in activities. This workbook is NOT a substitute for any other medical care that has been recommended for the treatment of your condition.

You will benefit most from this workbook if you commit yourself to completing all the sessions within a 6 week period of time. Scientific research tells us that these courses are of great benefit to people living with chronic diseases such as diabetes, arthritis and HIV/AIDS. But to benefit from the course, using the workbook regularly over 6 weeks and participating in activities is essential. The workbook is divided into six sections:

1. Week 1: Self-management and Exercise
2. Week 2: Managing common symptoms of HIV/AIDS
3. Week 3: Stress Management
4. Week 4: Pain
5. Week 5: Eating Well
6. Week 6: Continuing as a successful self-manager

Your course leader is _____. She has been trained in all the information you will be going through. She has also been trained by a physiotherapist who specializes in HIV/AIDS in safe ways to exercise and in relaxation techniques.

Week 1: Self-Management and Exercise

What do we mean by the term “self-management”? Self-management does not mean that you are expected to look after your health on your own with no help. No, someone who is a successful self-manager takes responsibility for their health. This means that they choose to work with the health team, with their drugs and with themselves to live a healthy life (just like a manager in a business – they don’t do everything themselves, they work with a team).

There are lots of things you can learn to do which will help you to be a successful self-manager. First of all it is important to understand HIV and AIDS. You need to understand about the virus and the disease, how it is transmitted, how it can affect you and about the medications used to treat it.

The next step in being a self-manager is being able to think about this information in terms of how it affects you. The final step in being a self-manager is to think about what it is that you want to be able to do, decide how you are going to do it and then to learn and practice the skills you need to be able to do it. Some of the things you will learn about and practice every day when you do this course include exercising, relaxation techniques and healthy eating.

Using this workbook you will learn about exercise and its benefits, in the second section you will learn a bit about the common symptoms of HIV/AIDS and how to manage these. The third section will focus on stress management, the final sections focus on pain, and eating well. Some people using this workbook may already know a lot about these topics, others may not know very much. It is important to share information and make sure that everyone has the knowledge they need to become a self-manager, even if you think you know a lot about these topics it is still worth your going through the workbook to make sure you have not missed out on any information. Scientific research tells us that people who are well informed about their health manage better and have a better quality of life. Using this workbook, you will also learn about and discuss the steps that are needed to become a good self-manager. Let’s look at these steps here.

Self-management steps

Step 1:

To be good at self-management you need to learn and practice several skills which you will practice through this course. The first step is to decide *what* it is you want to be able to do. This can be the hardest step to think about. For example you might be feeling very sad and depressed. First you need to think about why you are feeling that way. Perhaps one of the reasons you are feeling that way is that you have lost touch with your friends. Your first step might be to decide that you need to meet people to make friends. This will help you to feel less sad and depressed.

Write down here three things that you want to be able to do:

1) _____

2) _____

3) _____



Step 2:

But deciding that you are going to meet people and make friends doesn't mean it will happen. You have to make it happen. The second step in being a self-manager is to decide *how* you are going to do it. Sometimes the thought of doing something new can seem too much and we don't even try. If you want to meet people to make friends you need to think about all the different options you have to do this. For example you could invite your neighbours for tea, or you could decide you would meet people by going to church, by joining a support group or an exercise group. Never assume that what you want to be able to do is impossible. Always look for every option and look at it from every angle.

Write down here three different ways that you could try to achieve what you want to do:

1) _____

2) _____

3) _____



Now that you have decided on *how* you can try to achieve what you *want*, you need to make an action plan. It is important that this plan is realistic otherwise it is likely you will not succeed. How do you do this?

- First decide what you are going to do *this week*
- Now make a *specific plan*

Saying that this week I'm going to try to meet some people is NOT a specific plan. To be specific, the plan must have different parts. It is useful to ask yourself some questions to help develop a specific plan. Questions like:

- *What?*

Exactly what are you going to do? For example you could decide that to meet people you are going to invite your neighbour for tea.

- *How much?*

Then you must decide how much you are going to do. For example are you going to invite one neighbour for tea or are you going to invite lots of neighbours over. Lots of people are much more tiring than one person. Or do you want to invite your neighbour for lunch? But lunch means a lot more preparation and time and will make you more tired. So you have to decide how much you can do.

- *When will you do it?*

Then you must decide on exactly which day you are going to do the activity and at what time of the day. Maybe it is better to invite your neighbour for tea in the morning because you get tired in the afternoon. Or if you feel sick in the morning from your medicines maybe it is better to invite your neighbour for afternoon tea. Or maybe your neighbour works and you need to invite them for tea at the weekend.

- *How often?*

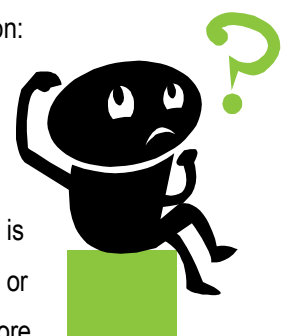
This is always the hardest part. We all would like to be able to do more things every day. But we are human and this is not always possible. When people want to start exercising, we often say we are going to do it every day. But this is often just not possible and if we then miss a day we feel that we have failed and we give up. How often will you invite your neighbour for tea? Not every day but maybe once a week. You know that you won't become friends immediately and that it will take time.

- *Is it a good plan?*

To test whether you have come up with a good plan you need to ask yourself this question:

"If I give myself a score from 0 -10 for how confident I am that I will achieve my plan this week, where 0 is not at all confident, and 10 is totally confident. What score will I give to show how confident I am that I can complete this plan?"

If your answer is 7 or more out of 10 then this is probably a very good plan. If your score is less than 7 you need to think about why you are not confident. What are the problems or barriers? Can you change the plan or solve the problems to make yourself feel more confident?



Step 3:

Now, write your plan down and put it somewhere you will see it every day. There is an action plan form at the end of this section and 5 more at the back of this book. Use them every week you are doing this course. You can always draw more of them to keep working on your plans in the future.

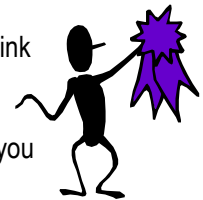
A good action plan is:

- Something I want to do
- Something I can expect to do this week
- Is specific
- Answers the questions: What? How much? When? How often?
- I am confident that I can achieve with a score of at least 7 out of 10.

Now you need to carry out your action plan. If it is a good plan then doing it is usually fairly easy. It helps to tell family or friends what your plan is and to report back to them on how you are doing. On this course you are going to make a plan every week and record how you get on. It helps to report back on things because you can then have an idea on how well you are doing. If you haven't been able to keep to the plan you can discuss the problems you might have had and make plans to cope with them.

Step 4:

Always check your results and give yourself a reward for having achieved your plan. Also think about how achieving your plan is making you feel. In the example we talked about, you could congratulate yourself for having invited your neighbour for tea, you would also think about how you now feel. Is the plan helping you to achieve what you want?



What about problems?

What if your plan doesn't work? Are you going to give up and decide you had a bad plan? There are seven steps to solving problems. These are:

1. Deciding what the problem is (you might need friends and family to help here)
2. List ideas to solve the problem
3. Select one idea to try
4. How did it go?
5. If it didn't work, try another idea
6. If your ideas don't work, ask friends, family, counsellors, professionals for ideas
7. Finally you might have to accept that you can't solve the problem now.

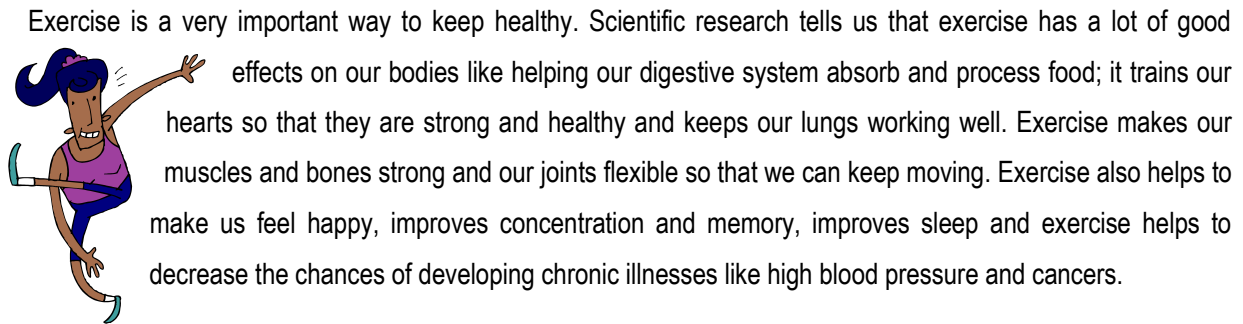
A successful self-manager is someone who:

- Sets goals
- Makes a list of ways to achieve those goals
- Makes action plans to achieve the goals
- Carries out the action plans
- Checks on their progress every week
- Can change the action plan if there are problems
- Gives themselves a reward for achieving their goals

At the end of each section and at the back of the workbook there are “Action Plan Forms”. Use these forms to plan what you want to do and how you are going to do it. We are now going to discuss exercise – use the “Action Plan Form” at the end of this section to plan what exercise you are going to do this week.



Exercise



Exercise is a very important way to keep healthy. Scientific research tells us that exercise has a lot of good effects on our bodies like helping our digestive system absorb and process food; it trains our hearts so that they are strong and healthy and keeps our lungs working well. Exercise makes our muscles and bones strong and our joints flexible so that we can keep moving. Exercise also helps to make us feel happy, improves concentration and memory, improves sleep and exercise helps to decrease the chances of developing chronic illnesses like high blood pressure and cancers.

In the past, when people became ill with a chronic illness like high blood pressure or diabetes or HIV/AIDS, medical care focused on helping them when their symptoms became worse. Treatment focused on using drugs and people were often advised to rest or decrease their activity. Today we know that if we teach people who develop chronic illnesses about their disease and encourage them to do exercise we can prevent a lot of the problems which used to be treated with medicines. We also know that exercise can help to treat a lot of the symptoms which people with chronic diseases develop. Symptoms which may be caused by the disease or by the drugs used to treat the disease.

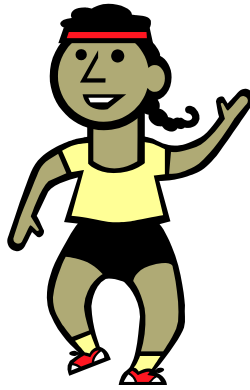
You may be wondering if it is safe for you to exercise when you have an illness like HIV/AIDS. Research tells us that **it is safe for people living with HIV/AIDS to do exercise**. Not only is it safe, it also stimulates the immune system, improves endurance and decreases fatigue, improves strength and decreases body fat. We also know that strengthening exercises seem to help prevent or decrease lipodystrophy in people who are taking ARVs (Lipodystrophy means that your body stops storing fat in places where it normally stored it (like in your buttocks) and begins to store the fat in places like your chest or your stomach). We know that people who are physically fit get fewer colds and take fewer days off work because of illness. One of the biggest benefits of exercise is that exercising regularly makes you feel more in control of your life.

Although exercise is good for you and safe for you to do, sometimes your body will give you clues that you need to cancel your exercise. If you have a fever, feel dizzy, have vomiting or diarrhoea, if your joints have suddenly become swollen, or if you have a pain which is new and you are not sure what is causing it, it is better to miss an exercise session until you can speak to a nurse or doctor.



Exercise is good for:

- Improving mood
- Strength
- Improving sleep
- Concentration and memory
- Heart and lung health
- Decreasing body fat
- Digestion
- Increasing confidence to self-manage chronic illness.



Do not exercise if:

- You have a fever
- You are dizzy
- You have been vomiting
- You have diarrhoea
- Your joints have suddenly become swollen
- You have a new pain which you don't know the cause of

Miss one exercise session if you have one of these problems until you can speak to a nurse or doctor. This does not mean you should never exercise but you need to make sure you are not becoming ill.

What kind of exercise should you do?

You do not have to join a gym or a club to get exercise. There are lots of ways of exercising from formal sports like running, playing football or netball, swimming or playing tennis. But, walking is also a very good way to exercise. Any activity which makes your heart beat faster and makes you breathe a little harder is exercise. Dancing is exercise, walking up the stairs is exercise, gardening is exercise. There are lots of ways that we can exercise every day without having to go to a class or join a club. You could walk a little further before catching the bus or the taxi or you could play with your children!

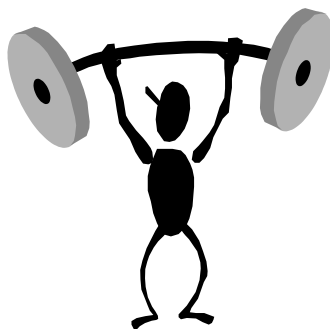
There are three general kinds of exercise you can do. Endurance exercise; like walking, running, dancing or swimming. Endurance exercise is sometimes called aerobic exercise which means that you will be breathing faster and your heart will be beating faster too. We know that this kind of exercise is very important to keep healthy and we need to do 30 minutes of this kind of exercise three times a week to keep healthy. The second kind of exercise is strengthening exercise. This kind of exercise focuses on making us stronger. To make muscles stronger we have to do exercises which make the muscles work hard against a resistance, like weight training but you can also do strength training by working with heavy bags of shopping! The last kind of exercise is stretching exercise. Stretching exercises focus on keeping us mobile and flexible.

Types of exercise:

- Endurance exercise which makes you breathe harder (sometimes called aerobic)
- Strengthening exercise which makes you stronger
- Stretching or flexibility exercise which makes you more mobile and supple



Endurance



Strengthening



Flexibility

There is an extra reason for people living with HIV/AIDS to do strengthening exercise. Scientific research tells us that strengthening exercises seem to help to prevent or limit lipodystrophy. Lipodystrophy means that your body stops storing fat in places where it normally stored it (like in your buttocks) and begins to store the fat in places like your chest or your stomach. Lipodystrophy doesn't just change the shape of the body, we also know that people who develop lipodystrophy tend to have high cholesterol and low insulin meaning that there is a bigger chance that they will have heart problems or develop diabetes. The exact cause of lipodystrophy is not clear but it seems to occur with certain HIV drugs, in older people and in people with a low T cell count who have been HIV+ for a long time. The most recent research tells us that if you do weight training (which builds up more muscle) you can limit lipodystrophy. This is a very good reason to make sure you do strengthening exercises in your exercise routine.

We know one of the hardest things about exercise is not doing it once, but doing it again and again. There are several steps we can follow to make sure that when we start to exercise we stick to it. We all make lots of excuses why we can't exercise. Let's look at the most common excuses.

"I don't have time"

It doesn't take a lot of time to start exercising. Five minutes a day is a good start. We make time to take medicine because we know without it we would become ill. Exercise is as important as medicine to help us remain healthy (remember it can never replace your drugs). If we know that it is that important we can make time for it.



"I'm too tired"

When people become ill they often become less active. As you become less active, your body loses fitness and you become weaker, you may feel stiffer and you tire more easily. This means that exercising might feel harder and so you exercise less. This often results in a downward spiral of activity and people often get to the point where even walking down the street to visit the neighbour can feel like too much. Being active or doing exercise when you are feeling tired will give you more energy and make you feel less tired.



"I'm too sick"

You may be too sick to undertake very vigorous exercise but you can still aim to be more active. You can even break your exercise into one minute sessions which you repeat several times through your day. The fitter you get, the better you will be able to cope with your illness



“I get enough exercise already”

You may be getting a lot of exercise already in your job or simply walking around doing your daily chores. But for most people if we add this time up, it still isn't enough exercise to keep them fully fit. This kind of exercise also doesn't include one of the most important components that make exercise good for us – fun!



“Exercise is boring”



You don't have to do the exercises that everyone else does if they are boring. Choose something that is fun, exercise with a friend or with your favourite music or listen to the radio. You can also keep your exercises fun by changing them regularly.

“Exercise is painful”

Exercise may be uncomfortable but it shouldn't be painful. If you have pain before you start to exercise, it should not get worse while you are exercising. If you do not have pain before you start to exercise and you start to feel pain while you exercise you need to stop exercising and evaluate your pain using the guidelines in Week 4: Pain. If you have muscle or joint pain for more than two hours after you exercise then you have probably done too much. Next time do a little less, either exercise for less time or less vigorously.

“It's too dangerous, it's too hot, it's too cold”

There are always reasons like this not to exercise. Remember that exercise can be done anywhere and anytime. You can put on music in your home and dance, if its too hot you could walk around shops which have air-conditioning. Finding a group of people to exercise with will not only make it safer but also more fun!



“I know I won't stick to it so there is no point in starting”



First review the steps we discussed on how to be a successful self-manager. If you set your exercise goals using these steps you have more chance of sticking to your exercises. Remember too the important step of rewarding yourself for achieving your goals, this makes it easier to move on to your next goal. We are now going to have a look at the important steps to take to be successful at putting your exercise plan into action.

Steps to success with exercise:

- Set a clear goal using the steps outlined in “How to be a successful self-manager”
- Choose exercise or activity that you want to do and that is fun
- Set a specific time and place to do your exercise
- Decide how long you are going to stick to the plan before you think about changing it (6 to 8 weeks is a good time to work on things)
- Keep an exercise diary to keep track of how you are doing (there is one at the back of this booklet for you to use)
- Keep track of your progress using the exercise diaries in this workbook.
- Start – don’t wait, start now. Begin gradually and proceed slowly
- Revise your programme. At the end of the 6 – 8 weeks make a new plan for the next 6 weeks
- Reward yourself. It is a reward to feel better and healthier but also give yourself a reward for achieving your goal, like eating a favourite meal, or visiting a friend or taking a walk somewhere special.

Your exercise programme:

An exercise programme should include the three different types of exercise; remember they were endurance, flexibility and strength exercise. Following the steps in the box “Steps to success with exercise”, you need to decide on what you want to be able to do and what exercise you would like to do. Now that you know what exercise you are going to do, you need to decide how much to do. The amount of exercise you are going to begin with will depend on a lot of different things. If you have not done any exercise for a long time or have been feeling unwell, have had difficulty breathing or been short of breath, if you have had stiffness or pain or weakness that interferes with your daily activities then you need to start your exercise slowly. You can begin slowly by starting with some flexibility and strengthening exercises. Do these exercises every other day for 5 minutes. Once you can do that comfortably and without feeling stiff or sore the next day, increase it to 10 minutes. Once you can do 10 minutes comfortably, you can start doing the exercises every day (when we say exercise every day, we usually mean exercise for 5 days of the week; it can be very hard to keep a routine to exercise on weekends when activities are different). Once you can do at least 10 minutes every day then you are ready to begin endurance exercises. Choose your exercises from the ones set out in the sections below. Follow the instructions in the box to make sure you get the most out of the exercises and do them safely.

Getting the most out of your flexibility and strength exercises:

- Move slowly and gently. *Do not* use jerking or bouncing movements as these will make your muscles shorter and tighter.
- Stretch to the point of *tension* in a muscle and hold for 20 seconds before you relax
- Don't push until it hurts, *stretch to tension not pain*
- Start off with 5 repetitions of each exercise. After 1 week increase it to 7, after another week increase to 10.
- Always do the *same number* of exercises on the left side and the right side of your body
- *Keep breathing*; do not hold your breath when you exercise. Think about breathing out as you move to make sure you do not hold your breath.
- Use the *two hour rule*. If you have increased symptoms for more than two hours after you exercise you have probably done too much. Don't stop doing the exercises but decrease how much you do next time.
- If you find an exercise difficult this does not mean you should not do it at all. You should adapt it, do it as completely as you can.

Flexibility Exercises:

Remember, these exercises are aimed at improving your ability to move. There is a long list of exercises that could be included here and you might not be able to do them all every time you exercise. Try to ensure that you do flexibility exercises at least once a week.



Strengthening Exercises:



You do not need to go to a gym to do strength exercises, the exercises described here can be done at home. To make muscles stronger you must make them work against a resistance or a force – they have to push or pull. You should not do strength exercises every day, rather they should be done every second day. Your muscles need a day of rest to adapt and get stronger. To make a muscle stronger you need to repeat each exercise 5 times to start with.

Once you can do an exercise 10 times you will not get stronger by doing more exercises. Now you will need to add more resistance to the exercise to get stronger.

Endurance Exercises:

The most difficult thing for most people is deciding how much exercise to start with. The easiest starting point is to ask yourself the question: “how much do I think I can do without suffering for it tomorrow?” If you feel you can do 5 minutes, then do 5 minutes. Remember that any exercise is better than none. You don't have to do 30 minutes from the first day. It is important to start slowly and increase very gradually. It is better to start off by doing less than you think you can and increase it from there.

There are three things you need to think about when you do endurance exercise. These three things are *frequency* (how often am I going to do this exercise); *duration* (how long am I going to exercise for when I do exercise) and *intensity* (how hard am I going to work when I exercise).



Frequency:

Try to do endurance exercise 3 or 4 times a week. By doing this you can rest every second day and allow your body to recover. All athletes have at least one day a week when they rest. Rest does not mean that they lie in bed all day though, it means that they do not do their exercises.

Duration:

How much can I do without suffering for it tomorrow? That is your starting point. If you are starting with just a few minutes you can gradually increase it over time until you can do 30 minutes at a time. The easiest way to increase the time is to use intervals of exercise. For example to walk hard for 3 minutes, then walk slowly for 2 minutes, then walk hard again for another 3 minutes. Slowly over time cut down the slow walking and increase the hard walking. You could also break your exercise into separate sessions. You could walk for 10 or 15 minutes in the morning and do it again in the evening. This would still count as 30 minutes of exercise.

Intensity:

How will you know that you are exercising hard enough to be doing some good? How will you know if you are exercising too hard? When doing endurance exercise the easiest way to check the intensity is to use the “Talk Test”. When you are doing moderate intensity exercise you should be able to talk comfortably but if you tried to sing it would be a little difficult and you would have to stop singing to take bigger breaths. Moderate intensity means you should feel that you are breathing a little faster and a little harder but you can still talk. It may take you a while to find the right intensity for you for the whole of your exercise session. This is normal; take your time to get to know how your body will respond.

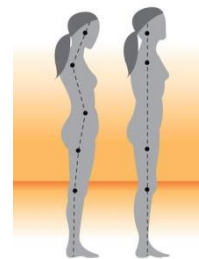
How will you know you are improving in your exercises? For the flexibility and strength exercises it is easy to feel the improvements as you will feel that moving is easier and you are stronger and can lift heavier items. For some people it is harder to know if you are improving with the endurance exercises. One way to see if you are improving is to do a test. One of the easiest tests to do is a timed test. Decide on a route that you can walk near your home. Walk this route at a moderate intensity and time how long it takes. After several weeks of exercise walk the route again and time it again. You may see that you can walk the same route faster within 4 weeks, but it may take 8 to 12 weeks before you see that you can do the route in a faster time. The goal is to complete the same route faster or in the same time but at a lower intensity (breathing much easier).

Use the exercise diary at the end of each section to record your goals and your progress in achieving them.

Exercise Routine

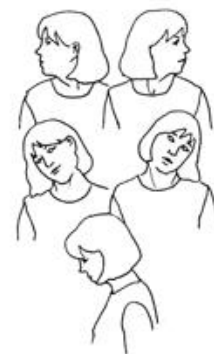
This is a 20 minute exercise routine which is safe for people living with HIV. This routine includes exercises which make you stronger (strength exercises), more flexible (stretching exercises) and fitter (endurance exercises).

1. Start by standing up straight and tall, feel your weight across your feet, relax your shoulders and open your chest, hold your head straight. Take a deep breath in and breathe out.



2. March on the spot for 2 minutes. March at a steady pace – that is a pace which you can maintain for 2 minutes. Do not start fast and get slower or start slowly and get faster. Pace yourself, start and finish at the same speed. You should be marching so that you can feel you are breathing a little bit harder than normal, you should be able to talk but not be able to sing.

3. Now stretch your neck – keep your shoulders relaxed and turn to look over your right shoulder – hold it for 20 seconds. Bring your head back to the middle, then turn to look over your left shoulder – hold it for 20 seconds and then bring your head back to the middle. Now put your left ear on your left shoulder - hold it for 20 seconds and then bring your head back to the middle. Repeat to the right. Now put your chin on your chest - hold it for 20 seconds and then bring your head back to the middle. Roll shoulders forwards 5 times, then roll your shoulders backwards 5 times.

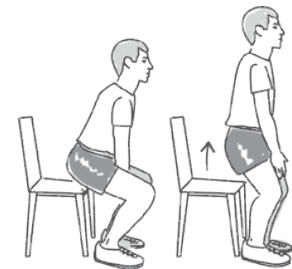


4. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your knees up as high as you can. Keep changing every 30 steps.

5. Stretch your body – with your feet shoulder width apart, slide your right hand down your right leg so that you bend sideways. Bend as far as you can - hold it for 20 seconds and then stand up straight again. Repeat this to the left. Put your hands on your bottom; bend your body backwards as far as you can. Now bend forward and try to touch your toes.



6. Sit on a chair – now stand up, keep sitting down and standing up for 2 minutes. Stand up and sit down at a steady pace – that is a pace which you can maintain for 2 minutes. Do not start fast and get slower or start slowly and get faster. Pace yourself, start and finish at the same speed.

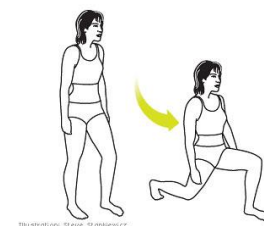


7. Lie down on the floor with your knees bent and your arms crossed on your chest. Lift your head to put your chin on your chest, now lift your shoulders off the ground. Slowly lower down. Keep going for 2 minutes.



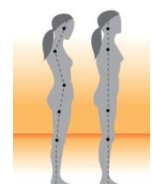
8. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your feet up as high as you can (try to kick your buttocks). Keep changing every 30 steps.

9. Stand up straight. Take one big step forward with your right foot and bend your knees so that your left knee almost touches the ground (lunge). Push back with your right leg to bring your feet back together again. Repeat on the left. Do 10 lunges on each leg.



10. March on the spot for 2 minutes – 30 steps normal, 30 steps lift your knees up as high as you can. Keep changing every 30 steps.

Finish by standing up straight and tall, feel your weight across your feet, relax your shoulders and open your chest, hold your head straight. Take a deep breath in and breathe out.



Action Plan Form - Exercise

Use this form to develop an action plan on exercise. What exercise would you like to do?

Be sure your action plan includes:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

How confident are you that you can complete this action plan?

Not at all												Totally
confident	1	2	3	4	5	6	7	8	9	10	confident	

Keep a record of how you did:

	I Plan to.....	I did.....
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Week 2: Managing Common Symptoms of HIV

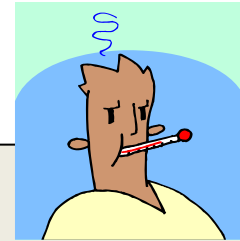
When something that is happening to our bodies that is unusual or not right, we develop symptoms. Symptoms include things like have a fever or temperature, feeling nauseous, vomiting, feeling tired, having pain, having a skin rash, coughing or struggling to breathe, feeling depressed and many, many more. People living with HIV/AIDS are likely to have many different symptoms which need to be managed. In this section, you will learn about *some* of the more common symptoms which people living with HIV/AIDS experience. You will also learn how to manage these symptoms. If you start feeling a symptom which is not described in this section then it is best for you to go to your clinic to get your symptom checked by a doctor or nurse.

The symptoms that people living with HIV/AIDS get can be put into one of three groups. The symptoms may be a side-effect of the medicines that you are using. Information on the side-effects of medicines can be obtained from your clinic and from other support and treatment literacy groups such as the Treatment Action Campaign (TAC). The second possible cause of symptoms is HIV-related infections. You might have a cough because you have developed pneumonia or TB. The third possible cause of symptoms may be the HIV itself. People with chronic illnesses like diabetes, high blood pressure, arthritis and HIV will all get symptoms related to the illness. These symptoms tend to increase and decrease over time. Research tells us that all symptoms can be managed better by following a good programme for living well as using the steps described in this workbook.

Symptom Management

All of the different activities described in this workbook will help you to live well and manage different symptoms. Exercise, eating well, using relaxation techniques and managing stress are all important to help prevent new symptoms from developing. Before we go through the most common symptoms which people with HIV/AIDS experience, there are a few principles to keep in mind when you experience a new symptom. If it is a new symptom, it could be a sign that you are developing an infection or it might be a side effect of a drug. Use the information in this section to help you decide on what action you need to take for the new symptom. It might be something that is safe for you to manage to home, or it might be something that you need to go to the clinic for, or you might manage at home for a while but if it doesn't get better then go to the clinic. Use the charts in this section to help you decide on how to deal with some of your symptoms

If you start experiencing a symptom you need to take time to think about it. Is this a new symptom, one you have experienced before or a symptom you have had for a while which is getting worse? You can do a FAST check (as described in the box below) on any new or worsening symptoms.



FAST check for new or worsening symptoms:

Fever	Do you also have a fever which started with the new symptom? (temperature of more than 38°C)	Having a temperature or fever can be a chronic symptom of HIV/AIDS. But if a fever starts with another symptom it can be an important clue that you have developed an infection.
Altered mental status	Have you also noticed a change in your mental state with the new symptom?	The brain is a very sensitive part of the body. Altered mental status is the term used to describe feeling confused, dizzy, and very sleepy. It can also mean more severe problems like coma or experiencing seizures or fits. You may need your friends or family to help you assess this.
Severe	Is this symptom much more severe (worse) than anything you have had before?	Symptoms come and go but if it is much worse than ever before you need to have it checked.
Typical	Is this symptom not typical for you?	Anything that is totally new and you have never had before, it is best to discuss it with a health care practitioner. You can use the charts in this workbook to decide whether you need to go to the clinic immediately or if you can wait until your next planned visit.

Once you have done your FAST check you can then use the action charts in this section to help you decide what to do next. When you read the action charts, you need to start at the top and follow the arrows depending on your answers to the questions. Do not jump around the chart as this will lead to mistakes. You will see on the chart that some symptoms mean that you need to go to your clinic straight away (now), some symptoms you need to go to the clinic today, and some symptoms you can manage yourself at home until your next routine clinic appointment. If you have more than one symptom, check the charts for all the symptoms and follow the most conservative (safest) advice. If your symptom is not described in this workbook then go to the clinic today to get it properly assessed. We will now discuss some of the symptoms in alphabetical order.



Breathing problems and coughing

Your body uses coughing to protect your lungs and to remove abnormal things from your lungs. Anything that irritates your lungs can cause you to cough. Coughing might bring up infected pus or mucous from the lungs which is useful. Coughing can be a side effect of medication used for high blood pressure too.

Smoking is one of the most common causes of coughing as the smoke kills cells in the breathing tubes to the lungs. This can happen even in people who are not smoking themselves but are breathing in other people's smoke. Other common causes of coughing are "colds" and "flu" which often cause yellow or white mucous.



Infections of the sinuses (the passages of the nose), can cause coughing because the mucous drips down from the back of the nose into the throat and lungs which irritates them and makes you cough. This is usually worse at night. Another common cause of coughing is hay fever. Hay fever is more common in spring and when it is windy. Dust from tree flowers (pollen) and plant seeds in the air make it

worse. If you are coughing because of hay fever, you will also have either itchy, red eyes and / or a bit of a sore throat with sneezing. The clinic can provide you with anti-histamine medicine to help with this.

Cough Action Chart:

Are you also short of breath at rest or short of breath with walking around?	Yes →	Go to the clinic now
No ↓		
Is your cough dry and do you also have a fever?	Yes →	Go to the clinic today
No ↓		
Do you also have a fever and pain in your chest with your cough?	Yes →	Go to the clinic today
No ↓		
When you cough do you cough up thick, bad-smelling brown or green mucous?	Yes →	Go to the clinic today
No ↓		
Have you had a fever for more than 4 days or has your cough lasted for more than 10 days?	Yes →	Go to the clinic
No ↓		
Treat your cough at home		

People living with HIV/AIDS are also vulnerable to developing lung diseases which cause coughing. The first serious cause of coughing in people living with HIV/AIDS is TB. Tuberculosis of the lungs (TB) causes a cough which lasts a long time with a fever. If you have a cough which lasts for **more than 10 days** then TB should be suspected and you should go to the clinic. The second serious cause is *Pneumocystis pneumonia* (PCP). PCP causes a dry cough (there is no mucous) with a fever and shortness of breath. Take a look at the “cough action chart” and you will see that any cough that also has a fever means you need to go to the clinic straight away.

Home treatment for a cough: You can treat your cough at home by making sure you are not dehydrated. If you do not have enough fluid in your body it will make the mucous in your lungs dry and sticky and more difficult to cough out. Drinking a lot of water will help with this. If you have a shower then having a hot steamy shower may also help, or steaming with hot water or rooibos tea will help. If you have a dry cough with tickling in your throat, it may help to suck on cough lozenges or on a hard sweet.

Depression:

It is common for people living with HIV/AIDS to become depressed but this is often not picked up by the nurses and doctors at the clinic. It is important for you to tell your nurse or doctor if you think you have depression. Depression is an illness, it is not simply the shock, scared, lonely and stressed feelings you probably experienced when you first heard your HIV status. Those feelings are a normal reaction to learning about your status. Depression develops over a few weeks and is a general feeling of depressed mood which happens with physical symptoms. This is caused by an imbalance of chemicals in the brain. See the depression checklist below – if you think you have depression and you have many of these symptoms then you probably have some degree of depression. This can be treated with medicine and psychological support. It is not something to be ashamed of. Go to the clinic and tell the nurse or doctor how you are feeling so that they can start you on treatment.



Dementia is very different from depression. With dementia your thinking is affected so that you struggle to communicate, you may struggle to pay attention and forget things a lot. You may also find it hard to move, be clumsy, lose your balance or even find that you can't move at all (paralysed). Your personality might also change. People who develop dementia generally do not feel depressed as they are usually not aware that they are unwell. Dementia is treated with ARV's.

Depression Check List:

- Do you feel down most of the time?
- Do you lack enjoyment with fun things like music, soccer or chocolate?
- Do you try to find peace by overeating?
- Or do you lack appetite and lose weight?
- Do you sleep badly at night?
- Do you struggle to get up in the mornings?
- Do you feel angry and agitated very quickly?
- Do you feel very passive?
- Do you lack energy every day?
- Do you struggle to concentrate?
- Is it difficult to make decisions about simple matters?
- Do you feel guilty?
- Do you feel worthless sometimes?
- Do you think of death a lot?
- Do you think of killing yourself?



If you answer yes to many of these questions, then you may have some degree of depression.

Speak to the doctor or nurse at the clinic about how you are feeling.

If you answer yes to one or two of these questions then you may have depressed mood which you can manage with some of the techniques described in the section on stress management.

Home treatment for Depression: There are many things you can do to help manage depression. Make sure that you get help straight away if you *feel like hurting yourself or someone else*. Often talking to a person who understand or to a health professional will help you through this mood. *Cut back on alcohol*, although it might make you feel better in the short term. In the long term it affects the way your brain works and you will not be able to escape the depression. *Keep active*, make you sure you get up every day, get dressed and get out of the house. Even if you don't feel like doing things, it's important to keep active, visit friends, and join a group. If you start to lose contact with people and withdraw your mood will only get worse. *Make plans for the future*, for tomorrow, for next week, for next month. Make sure you do *20 to 30 minutes of exercise* every day. As we said in Week 1, exercise is very important to keep us healthy and help our moods. Depression feeds on depression, when you believe that things will get better, they will start to change. Use the suggestions in the section on Week 3: Stress Management to help you manage your symptoms.

Diarrhoea (Running tummy)

Diarrhoea can affect anyone. Diarrhoea means you have to go to the toilet often and / or your stool is watery or slimy. Sometimes diarrhoea comes with stomach pains or with vomiting or both. When you have diarrhoea your body is losing water all the time. Losing water is called dehydration and can be dangerous, especially for children.

Diarrhoea can be because of infections, as a side effect of medicines or caused by poor absorption of food. Diarrhoea can be prevented by making sure that you are using clean drinking water, that you prepare food carefully (see the section for Week 5) and make sure that you wash your hands every time after going to the toilet.

Diarrhoea Action Chart:

Do you have?

- *Black or bloody stools*
- *Severe, steady stomach pain*

Yes



Go to the clinic now

No ↓

Do you have any signs of dehydration?

- *Extreme thirst*
- *Very dry mouth*
- *Dark urine*
- *Lightheadedness*

Yes



Go to the clinic today

No ↓

Are you taking antibiotics?

Yes



Go to the clinic

No ↓

Has the diarrhoea lasted for more than 5 days
without improving?

Yes

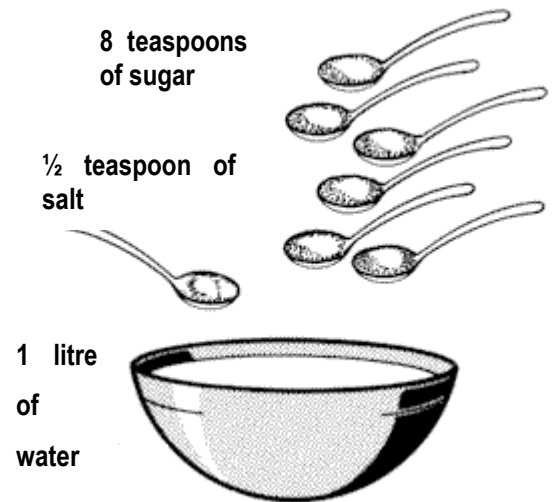


Go to the clinic

No ↓

Treat your diarrhoea at home

Home treatment for diarrhoea: The most important thing with diarrhoea is to make sure that you are getting enough fluids so that you do not become dehydrated. Try to avoid drinks with caffeine in them as they can cause more dehydration (coca-cola, coffee and tea all have caffeine). Drink your fluids at room temperature, hot drinks or cold drinks can make your diarrhoea worse. Making a **glucose drink** is the most effective treatment for diarrhoea. Make this by filling a clean one-litre bottle with clean water from a tap or boiled water if you are not sure that the water is clean. Add 8 teaspoons of sugar and half a teaspoon of salt to the water and mix it well. You can add half a cup of orange juice if you find you don't like the taste. Try to drink one to two cups (200ml) after each loose stool (bout of diarrhoea). Take small sips and drink it slowly.

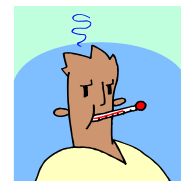


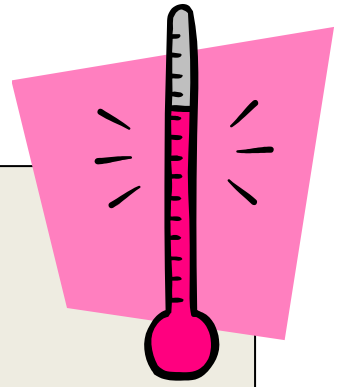
If you have diarrhoea you might not feel like eating but skipping food is not a good idea. Try plain foods like dry toast white rice noodles, mashed potatoes or white bread. Eat any food that doesn't make you feel sick. Make sure you wash your hands before and after handling food. Usually diarrhoea will go away on its own within a week.



Fever

Fevers or having a high temperature are most commonly caused by infection. In people living with HIV/AIDS the fever can be caused by the HIV itself but it can also be caused by other infections or even by medications. If you have a fever you need to check that you do not have any other symptoms of serious illness warning you to take action straight away. Use the fever action chart to check for these.





Fever Action Chart:

Do you have a fever and?

- Neck stiffness (you can't bend your neck to put your chin on your chest)
- Extreme tiredness or feel confused
- Fitting or seizures
- Severe irritability

Yes

Go to the clinic now

→

No ↓

Do you have a fever with a *dry cough and severe shortness of breath*?

Yes

Go to the clinic now

→

No ↓

Do you have a *new skin rash or skin sores* with this fever?

Yes

Go to the clinic

→

No ↓

Do you have any of the following with your *fever*?

- Headache
- Sore throat
- Cough
- Diarrhoea
- Urinary problems

Yes

See the action plan for that problem

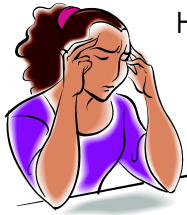
→

No ↓

Treat your fever at home

Home treatment for fever: A high fever can be treated by sponging the body down to cool it down, or by using medicine. Sponging the body down with luke-warm water (not cold water) helps to bring the temperature down. Paracetamol (Panado) can also be used to lower a temperature.

Headaches:



Headaches are one of the most common symptoms experienced by people both with and without HIV/AIDS. Headaches can be caused by muscles becoming tense, they can also be caused by medication. Headaches with fevers can be more serious. If you have a headache with a fever and stiff neck – *a neck so stiff that when you bend it forward you can't put your chin on your chest*, you may have meningitis. This is a serious infection of the lining of the brain which needs to be treated immediately. Use the headache action plan to decide how to manage your headaches.

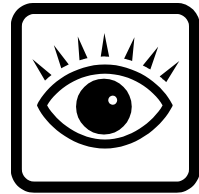
Headache Action Chart:		
Do you have a <i>fever and neck stiffness</i> with your headache?	Yes →	Go to the clinic now
No ↓		
Do you have any of these with your headache?		
• <i>Difficulty moving your arms or legs</i>	Yes	Go to the clinic now
• <i>Difficulty with seeing</i>	→	
• <i>Difficulty speaking (slurring)</i>		
No ↓		
Has your headache lasted more than 3 days?	Yes →	Go to the clinic
No ↓		
Treat your headache at home and discuss it at the clinic at your next routine appointment		

Home treatment for Headaches: Paracetamol is very effective to treat a simple headache. This medicine works better if you take it as soon as you feel the headache rather than waiting until the pain is so bad you can't take it anymore. If the headache is due to muscle tension and stress then rubbing the neck muscles and putting something warm on the neck (a hot water bottle wrapped in a towel) can help. Relaxation techniques and resting is also very effective to manage headaches.



Eye problems:

People living with HIV/AIDS can get many eye problems. All eye problems should be checked at the clinic. Eye problems can be caused by infection (CMV), but, eye problems can also be caused by medicines, high blood sugar (diabetes), headaches, eye strain and normal changes with ageing. If you develop eye problems *suddenly* then it is likely that this is caused by an infection and you need to go the clinic straight away. If your eye problems have come on slowly then you need to get your eyes checked the next time you go to the clinic.



Eye Problem Action Chart:

Did <i>blindness</i> (part or total) come on <i>suddenly</i> in one or both eyes or is <i>the loss of vision</i> severe?	Yes →	Go to the clinic now
No ↓		
Is your CD4+ count more than 200	Yes →	Go to the clinic
No ↓		
Have you had <i>gradual loss of vision</i> equally in <i>BOTH</i> eyes	Yes →	Go to the clinic
No ↓		
Go to the clinic NOW		

Nausea and Vomiting:

Many of the worries about nausea and vomiting are the same as for diarrhoea. Medicines are the most common cause of nausea in people with HIV/AIDS but this can also be caused by viral infections. Dehydration is the biggest risk. Signs of dehydration may be dizziness, severe thirst, dry mouth and tongue, decreased and very dark urine, wrinkled and dry skin. Black or bloody vomit can be a sign that there is bleeding in the stomach.





Nausea and Vomiting Action Chart:

Do you have any of these?

- *Black or bloody vomit*
- *Severe steady stomach pain*
- *Headache with a stiff neck (you can't put your chin on your chest)*

Yes



Go to the clinic now

No ↓

Do you have any signs of dehydration?

- *Extreme thirst*
- *Very dry mouth*
- *Dark urine*
- *Lightheadedness or dizziness*

Yes



Go to the clinic now

No ↓

Has this started after starting *new medicines*?

Yes



Go to the clinic

No ↓

Are you pregnant or do you think you might be pregnant?

Yes



Go to the clinic

No ↓

Have you been vomiting for *more than 3 days* without improvement?

Yes



Go to the clinic

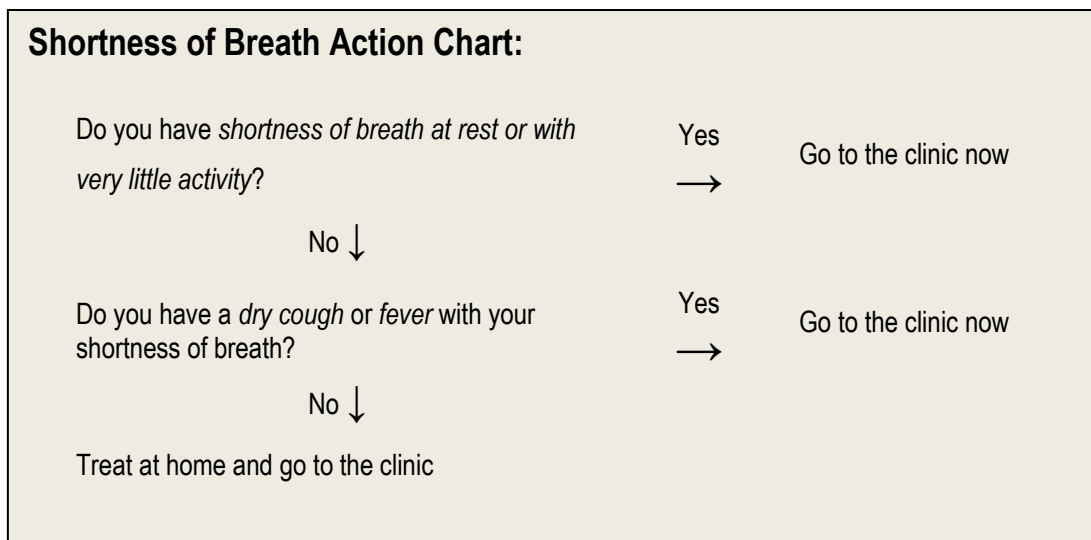
No ↓

Treat vomiting at home

Home treatment of Nausea and Vomiting: It is important to get as much fluid into your body as possible without vomiting again. Sipping the glucose drink described for diarrhoea is important. Don't try to drink a whole glass all at once, sip it slowly so that you do not vomit again.

Shortness of Breath:

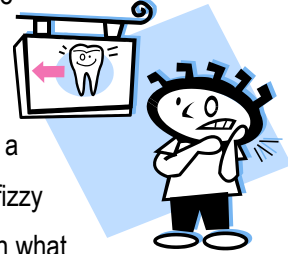
It is normal to feel short of breath when you do strenuous activity or exercise. If you get short of breath when you are resting or when you do very little activity or if you wake up at night feeling short of breath then you need to go to the clinic urgently. The main cause for this kind of problem in people with HIV/AIDS is PCP. Shortness of breath can also be caused by lung infections you have had in the past and smoking.



Home treatment for Shortness of Breath: If you are busy with something when you become short of breath you should not stop straight away or try to hurry up to finish. It is best to slow down what you are doing and see if your breathing settles down. Sometimes when we feel short of breath we worry about it which makes us afraid and can make our breathing even worse. If you have not been very active for a while, your shortness of breath might be a sign that you need to get fitter. You need to slowly increase your activity over time as discussed in the section on exercise. If you smoke and you are getting short of breath you need to try to stop smoking. If you are struggling with stopping smoking then speak to the nurse on your next visit to the clinic. If people smoke near you, try to avoid their smoke or ask them to smoke away from you. If you are short of breath it is helpful to practice the deep breathing exercises described in the section on relaxation. This kind of deep breathing helps to train the muscles for breathing and also helps your mind to manage your symptoms.

Sore Throat and mouth:

Sore throats are common in people with and without HIV. The most common causes of a sore throat are the cold viruses but a sore throat can also be caused by other infections. Most sore throats can be treated safely at home. A sore mouth and sore ears are also common. Patches in the mouth, white patches on the tongue or mouth or red burning patches which are itchy and sores in the mouth or down your throat can all be caused by thrush. Pain in the mouth can be caused by teeth with holes. Teeth can get holes because of bacteria in the mouth. You can prevent these by brushing your teeth twice a day and after every meal. It does not take much toothpaste (a drop the size of a pea is enough) to keep your teeth clean. It is also important to cut down on sweets and fizzy drinks which cause teeth to rot. Use the sore throat and mouth action chart to decide on what you need to do.



Sore Throat and Mouth Action Chart:		
Do you have severe difficulty breathing or swallowing?	Yes →	Go to the clinic now
No ↓		
Do you have a fever or pus in the back of your throat?	Yes →	Go to the clinic
No ↓		
Do you have pain in your teeth or swelling in your cheek?	Yes →	Go to the dental clinic
No ↓		
Do you have sores or white patches in your mouth, on your tongue or on your lips?	Yes →	Go to the clinic
No ↓		
Has your sore throat lasted more than 10 days?	Yes →	Go to the clinic
No ↓		
Treat at home		

Home treatment for a sore throat and mouth: Drinking cool liquids and taking painkillers like paracetamol can help. You can also treat a sore throat by gargling with salt water. It may also help to suck on ice cubes if you have access to ice.

Skin Problems:

There are many skin problems which can affect people living with HIV/AIDS. Very few of these problems are dangerous but because they can be seen they can be very upsetting. Being able to see these might make you feel unattractive or have low self-confidence, they often last a long time and can constantly remind you of your HIV status. The most common skin problems people with HIV/AIDS have are shingles, chicken pox, bacterial infections, warts, fungal infections and rashes.



Skin Problems Action Chart:		
Do you have a rash which is <i>painful</i> on one side of your body or on your face?	Yes →	Go to the clinic today
No ↓		
Has the rash started after starting new medicines?	Yes →	Go to the clinic today
No ↓		
Do you have a rash or blisters on your body and a <i>fever</i> ?	Yes →	Go to the clinic today
No ↓		
Do you have warts on your skin which are a different colour to your skin?	Yes →	Go to the clinic
No ↓		
Do you have a rash in a <i>circle</i> on your skin or <i>white dying skin</i> between your toes, in your groin, around your private parts or under your arms or is there <i>pus in the rash</i> ?	Yes →	Go to the clinic
No ↓		
Treat at home		

Home treatment for skin problems: It is important to keep the skin clean to prevent any infections developing. Wash your whole body with soap and water every day. Keep your fingernails short and clean. If you are scratching in your sleep, you can sleep with socks over your hands so that you do not damage your skin. If your skin is dry and itchy, it helps to wash with aqueous cream instead of soap.

Urination problems:

Urinary infections happen more often in women than in men, but men with HIV/AIDS are more likely to get these infections too. The most common symptom of a urinary infection is pain or burning when you pass water, frequent need to pass water and blood in the urine. These symptoms are not always caused by an infection; they can also be caused by too much caffeine (tea, coffee, cola); bladder spasms (when the bladder becomes overactive) and even anxiety. Bladder infection in women can also be caused by sexual activity. If you also have a fever, vomiting, back pain or teeth-chattering or body-shaking chills it is likely that the infection has spread from the bladder to the kidneys. Use the Urination Problems Action Chart to help you decide how to manage your symptoms.



Urination Problems Action Chart:

Do you have a <i>fever, vomiting, back pain, shaking chills</i> as well as <i>painful or frequent or bloody urination</i> ?	Yes →	Go to the clinic today
No ↓		
Could you be pregnant?	Yes →	Go to the clinic today
No ↓		
Do you also have a <i>new irritating vaginal discharge</i> ?	Yes →	Go to the clinic today
No ↓		
Do you have pain in your stomach (abdomen) as well as a vaginal discharge?	Yes →	Go to the clinic today
No ↓		
Treat at home and go to the clinic if it does not clear up in 2 days.		

Home water.
Drink h out
anyth mical
content of the urine. If you have a new vaginal discharge or pain in the abdomen it is important to go to the clinic as this means that the symptoms may not be coming from the bladder but from the vagina which needs medical treatment.

A final word on symptoms:

Remember the steps described in this section and the action charts do not replace nurses and doctors. The information in this section is to help you work **with** your health team. Use the action charts to help with thinking about any symptoms you experience and to help you decide what you need to do about them. As you have read, some symptoms it is perfectly safe for you to manage at home. Some symptoms you need to go to the clinic straight away for. If you have any doubt or any worries about any of the symptoms you experience then it is best to go to the clinic to get them fully assessed. Remember what you learnt in the first section on how to be a good self-manager. Use the information in that section to help you get the most out of any visit to the clinic about any symptoms you experience.



When you do visit the clinic for a symptom you may be treated by the nurse or doctor. Or may be referred to someone who specialises in the problem you are experiencing. In the next section, we will discuss how to communicate well with your health carer. No matter who you are seeing at the clinic, it is useful to use the steps on communication to get the most out of your clinic visit.

Use the “Action Plan Form” at the end of this section to plan how you will manage a symptom which you experience. Use the “Exercise Diary” to keep track of the exercise plan you started last week. Remember these charts are designed to help you become a successful self-manager!

Action Plan Form – Managing Symptoms

Think about a common symptom which you experience. Use this form to draw up an action plan of how you plan to manage this symptom the next time it occurs.

Be sure your action plan includes:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

How confident are you that you can complete this action plan?

Not at all											Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise Diary

Use this exercise diary to keep track of the exercise goals and plan you drew up in week one.

Start off by writing down your goal.

Write down here what you want to be able to do: _____

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)
_____ (*how much*)
_____ (*when*)
_____ (*how many?*)

	Exercise Planned	Exercise I did...	How did I feel? Do you need to change anything?
e.g.	20 mins in a.m. after breakfast and in p.m. after supper		Very tired by the second session, I'm going to cut it down to morning only for this week.
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 3: Stress Management

In our society, we talk about stress a lot. We might say that it is stressful to live in South Africa. That it is stressful to worry about our children or our families, it is stressful to worry about money or it is stressful worrying about getting a job or coping with my job. We use the word stress a lot, but what does it mean? Stress is a feeling; it is a combination of feeling tense and worried. When we feel stressed we may be irritable, and find it difficult to concentrate or remember things, stress can affect our sleep, our appetite and our relationships.



The most common reason why we feel stressed is a lack of control. We tend to feel that things are stressful if we don't have any control over them. We feel stressed if we are going to be late for work because the trains are late – this is out of our control. We feel stressed about where we live if we don't feel safe there – those who commit crimes against us are also out of our control. In the same way, we may feel stressed when we have a chronic illness like HIV/AIDS or diabetes or high blood pressure. If you feel that your illness is out of your control and there is nothing you can do to affect it, this makes you feel stressed.



Stress is not always bad. We know that stress can be useful too. For many people if we feel some stress, we might feel under pressure to perform better. You might feel stressed because your family is coming to visit, but this stress makes you tidy up your home – a good effect of the stress. Students who are studying will only complete their studies if there are exams and deadlines for assignments, without the stress of the deadline, the students would not complete the work.

Sometimes we wish for a “stress-free” life. But, we know that if there was no stress in our lives, if we did not have to do anything all day long, this would not be good for us either. If I lay in bed all day and did not do anything, my muscles would get weak, my joints would get stiff and I would become ill. We need some stress in our lives to keep us healthy. The important thing is to keep the amount of stress at a level that we feel we can manage. This is why we talk about stress management, *not* stress elimination!

There are many different things we can do in our lives to manage stress. The first step is to understand why we are feeling stressed. There are usually three things which affect how stressed we feel.

1. The stressful situation:

Usually the less you expect the situation and the less familiar you are with a situation, the more stressful it will be. If you needed to take the train to work but you knew the day before that the trains would be late, this would be less stressful than finding out after you have got onto the train that it is going to be late. If you think about having pain, if you know the cause of the pain is it more or less stressful? If you don't know what is causing your pain and you are worrying that there is something seriously wrong, is this more or less stressful?

2. How you see the situation and how you cope with it:

If the situation you are in is not important, you are likely to feel less stressed about it. If you are on a train which is going to be late, but you are going shopping on your own, then you are likely not to get so stressed about it. If you are on a train which is going to be late and you are going to work this might be more stressful, but if you have a cell phone with you and you have airtime on the cell phone and you telephone your boss to explain why you will be late, then this might be less stressful. Your ability to cope with the situation, affects the amount of stress you feel. While it is stressful to live with a chronic disease like HIV/AIDS, diabetes or high blood pressure, if you thought you could cope with it and it would not interfere with your job and your life would it be more or less stressful? Having knowledge about your condition allows you to think about it in a different way and will change the way that you cope.



3. Support from family and friends:



Friends and family who understand and support you will affect your levels of stress. Feeling alone and like you have no support will probably make you feel more stressed. If you think about living with HIV/AIDS, would it be more or less stressful if there were no one to support you? But, we do need to be careful about support from family and friends. If they take over doing everything for us (because they care about us and are trying to help), we might feel useless and like we don't have a purpose. Support does not mean doing everything for me.

Stress is not just the things that happen to us. The amount of stress that we feel depends on a lot of different things which can change every day. There are many different things we can do to manage stress every day.

Managing Stress:

1. Dealing with the cause of the stress



The first step in dealing with stress is to identify *why* you are feeling this way. Use the self-management steps to help you identify the problem. Once you know why you are feeling this way then you need to decide what you can do about it. Sometimes dealing with the things that stress us is easy, if you are friends with your neighbours and the noise from their television is irritating you it might be easy to ask them to turn down the volume. If you are not friends with your neighbours, or you are very shy it might be quite difficult to ask them to turn down the volume. Sometimes we can identify the things that stress us and do something about it. But, often we either cannot deal with it or it is out of our control. If you cannot deal with it or it is out of your control, the next step is to change the way you are looking at the problem.

The second step is to look at the problem in a different way. Think about how you are feeling. Are your thoughts and feelings about the problem inaccurate? Maybe you are very worried about your health, this is stressing you. Are you worried that you will be very ill and unable to work soon? Are these thoughts and feelings accurate? On what information are you basing these thoughts and feelings? Have you spoken to experts about your health or are you basing your thoughts and feelings and stress on poor information?

Step three is - plan your life. Do you get stressed by the same things over and over again? Or do you find yourself getting stressed because there are times when your life is very busy? If you are doing the same things over and over and getting stressed, you might want to look at how you are dealing with it and see if you can try a different plan. What about a busy life? This is also about planning, being very busy and having no time for ourselves, can be very stressful. Plan things over time carefully, make sure you have time to at least do some relaxation or exercise even when you are very busy. Do not leave things for the last minute.



The last step to deal with stress is to get help. Family and friends and support groups are a great way to decrease stress. If we want support from people though, we have to tell them clearly what the problem is and what we would like from them. Often we do not communicate clearly and this might make the stress worse! If you find your family or friends are not very helpful or supportive, it might be worth sitting down with them when you are not feeling stressed to talk about these things. It might be that they see things differently to you, this does not mean they are right and you are wrong, or that you are right and they are wrong. It just means that you see things differently and you can discuss how to handle things better. If having a discussion like this is difficult, it might be useful to ask a

counsellor to help with the conversation. You can ask for assistance at a clinic or you can go to an NGO like FAMSA who specialise in family and relationship counselling.

2. Relaxation

When we feel relaxed, we feel calm. Sometimes if we are relaxed and we are tired, we might feel sleepy. At other times we might feel relaxed and alert and be able to concentrate calmly on tasks. Relaxation can help us to concentrate and it can help us to unwind and go to sleep. Relaxation is a very useful way to manage stress and some of the symptoms of chronic diseases such as pain.

If we are stressed, this can make our muscles tense, our hearts beat faster and we breath faster, if we are also feeling unwell and have pain we will feel worse. Relaxation can decrease the tension in muscles and slow down our hearts and breathing and help to make us feel better. If we are stressed we often become irritable and moody, relaxation helps to calm you and make you feel more in control of your life. When we are stressed sometimes it is difficult to fall asleep as we are worrying about things out of our control, if you are also unwell, not sleeping will make you feel worse. Relaxation will help you get to sleep, this will help manage your stress and improve your health.



Just like learning to play a new sport or doing exercise, relaxation takes practice. The specific way that you relax doesn't matter; we are all different and might relax in different ways. The important thing is to practice it regularly. There are two different ways of relaxing described at the end of this section. You can do these at home in a quiet and comfortable safe place to begin with. But, once you get good at relaxation, you can relax in a crowded waiting room, on a train or a taxi. You can do relaxation anywhere!

Good times to practice relaxing are when:

- You feel you are getting tense or irritable or you are worried
- You feel you are in pain
- You want to go to sleep



3. Sleep

People with chronic illnesses often struggle to sleep because they are stressed and worried about their condition, they worry about what this means for them, for their family, for their future. People also often struggle to sleep because of the illness itself, perhaps you have pain, you feel sick or you may even be so tired you can't sleep. Some people find it difficult to get to sleep and only fall asleep very late at night, others find that they fall asleep but then wake up during the night and can't get back to sleep. Some people find it difficult to sleep at all at night and sleep during the day.



Sleep is very important to keep healthy. We all need different amounts of sleep. Some people need 8 hours of sleep a night, some may need 10 hours and some people only need 5 hours of sleep. We are all different. We have been learning how to fall asleep and sleep well since we were babies. If you do not sleep well, following these steps will help you to learn how to fall asleep and sleep well. Remember that like learning anything new, this will take time. It might take up to 3 months to learn to sleep well if you have been struggling with sleep for a while.

Suggestions for Improving Sleep

1. *Have a bedtime routine:* try to go to bed at around the same time every night and always do the same things before getting into bed. A bedtime routine could be to lock the house, get undressed, wash your face, clean your teeth, get into bed and do a relaxation session.



2. *You can't sleep because of worrying:* write down your problems or the things that are worrying you, then write down the next step that you think could help sort out the problem. If you wake up during the night worrying about the problem, remind yourself that you've gone over it and you have a plan. If you wake up with a new worry, write down that problem to deal with in the morning. Practice your relaxation to take your mind off the worry. If you still can't sleep, it may be better to get up and do something relaxing like reading, watching TV, listening to relaxing music or doing relaxation.



3. *Your bed and bedroom are for sleeping:* try not to use your bedroom during the day. Do not watch TV in bed. If you are not asleep within 30 minutes of going to bed, get up and do something else. Do not lie in bed and worry that you have not fallen asleep. This will only make you feel stressed and lessen the chance of falling asleep.



4. *Have a morning routine:* get up at the same time every day, even if you don't feel like it. Our bodies like to work on regular patterns to fall asleep and get up at the same time every day.

5. *Avoid drinks containing caffeine* for at least 4 hours before going to sleep (drinks like coke, tea or coffee).

6. *Never use alcohol to help you sleep.* It might make you feel relaxed at first, but once this wears off it is likely to make you feel jumpy and you are likely to wake up during the night.

Good sleep habits:

- Go to sleep at the same time every day
- Have a bedtime routine
- Do relaxation before going to sleep
- Use your bed only for sleeping or relaxing
- Have a morning routine

4. Exercise



Exercise is a very effective way of managing stress. People who exercise regularly doing at least 20 to 30 minutes of exercise, 3 times a week have less risk of suffering from stress related illnesses. Go back to the section on exercise for more on how to exercise safely and effectively.

Exercise:

- Decreases stress
- Helps us sleep better
- Decreases pain
- Makes us healthy and decreases our chances of developing other illnesses

5. Communicating with your health carer

Anyone living with a long term health problem, whether it is HIV or high blood pressure or diabetes will have to visit their clinic regularly. Visiting the clinic regularly can be stressful because it takes time, you have to plan ahead, you might not be sure how long you are going to have to wait, you might be worrying about what the health carers are going to tell you. One of the most important ways of managing the stress associated with visiting clinics and seeing health carers is to think about and plan how to communicate with them.



When visiting the clinic to see a health care practitioner it is important that you feel comfortable asking questions (any questions, even if you feel they are “silly” or “stupid” questions) and comfortable expressing how you feel. It is also important that you feel you can negotiate your treatment with your health care provider so that both you and the carer feel that you are receiving the best care for you. It is important that you not



feel that your health care provider is ignoring you, “puts you down” or treats you like a child. We know that doctors and nurses have a lot of patients to see and they have little time to spend with each person. One helpful way to make sure that you get the most out of your appointments with the doctor or nurse is for you to take PART – Prepare, Ask, Repeat, Take action.

Take PART:

Prepare:

Before your appointment at a clinic it is important to prepare. Think about the reason for your appointment and whether there are any issues in particular that are worrying you. Write down your questions or the things that are worrying you. You need to be realistic about the list you write down, there will probably only be time to answer one or two of the things on your list. Make sure the most important problems are at the top of the list. Take your list with you to your clinic appointment, then when the doctor or nurse asks if there is anything you want to ask, you can use your list.

If there are particular symptoms or health issues you want to discuss, prepare for your appointment by writing down specific information the doctor or nurse will want to know. Things that are helpful are: when did it start, how long do the symptoms last, where are they in your body, what makes you feel better or worse, have you had a problem like this before and how was it treated; have you changed anything such as your diet, exercise, medicines. If you have already received treatment for a problem, be ready to report back on how well it has worked, or on whether it has not worked at all.



Be open about how you are feeling and about the things that are worrying you. The more open you are, the more the health care provider can help you. Finally, give feedback. If you don't like the way you have been treated you can tell the doctor or nurse. If you do not want to tell them directly then you can speak to someone else in the clinic or to someone in a support group. Remember too that doctors and nurses and other health care providers also appreciate being complimented. If you feel that you have been treated well and are happy with your treatment, it is acceptable to compliment the health carer.



Ask:

Another important step in having good communication and decreasing stress is to ask questions. Having good information is essential to you being successful in self-managing your health. Ask questions about your diagnosis such as what is wrong, what has caused it, is it contagious and what is going to happen now? Then ask questions if you have had tests, what is the test for; what if I don't have the test and what will the test involve? Remember to ask questions about your treatment options, what are the benefits of treatment and what are the risks and side effects? Finally ask questions about follow-up, when should you return to the clinic, what should you watch out for and what should you do next?

If you find you have difficulty remembering information it is a good idea to write things down during your visit. Or you could ask someone you trust to come to the appointment with you to help with remembering.



Repeat:

One of the important things to do to help with remembering things is to repeat it. So if the nurse or doctor explains something to you, repeat back to them in your own words what you have understood. This is very useful to make sure there are no misunderstandings.

Take Action:

At the end of your appointment, it is important that you know exactly what you will need to do next. It might be that you need to make another appointment, or that you need to go home and change something or get new medicine from the pharmacy. Make sure that you are clear about what you need to do next, and then do it!

Relaxation

Long relaxation:

Find a comfortable position. Lie on your back or sit in a chair with your back supported.

Place your hands at your sides, palms up.

Close your eyes if you wish.

Now begin to become aware of your breathing..... Focus on slowing down the rhythm of your breathing.....

Your chest and tummy will expand outward with each breath, like a balloon gently filling with air....

Imagine your ribcage moving out to the sides when you breathe in.... and gently inward as you breathe out....

Slowly take a deep breath in.... Pause for a moment.... and then slowly breathe out. Let the tension melt away as you relax more deeply with each breath...

Continue breathing slowly and gently....

Now think about the top of your head. Feel the skin on the top of your head beginning to relax, and spreading slowly downwards....

Even your ears are becoming relaxed and heavy.... Feel your eyebrows resting....

Your forehead is becoming relaxed and smooth....all the lines on your face are becoming smooth..

Let your jaw relax by allowing your mouth to be slightly open.... Allow your tongue to relax...

Feel your throat relaxing.... relax your cheeks, nose, and eyes.... Feel your eyelids becoming very heavy.... and very relaxed.... more and more relaxed....

Enjoy the feeling of relaxation you are experiencing.

Now think about your neck.... allow a feeling of relaxation to begin at the top of your neck, and flow downward...

Feel the relaxation as your shoulders become relaxed and loose.... Let your shoulders gently sink downward.... as they become relaxed.... and heavy.... very heavy.... and very relaxed.... deeper and deeper.... relaxed....

Feel your collar bones becoming relaxed as your shoulders move gently back, and your chest widens slightly....

Allow all the muscles in your shoulders to feel smooth... and relaxed.... as the muscles give up their hold completely...

Notice your breathing once again... see how regular it has become... continue to take slow.... smooth.... deep breaths... Breathe in the feeling of relaxation... and breathe out any tension... your breathing allows you to

become more and more relaxed.... deeply relaxed..... Now turn your attention to your right arm..... Feel the relaxation flowing down from your right shoulder.... allow your upper arm to relax... your elbow.... lower arm... and wrist become loose and relaxed...

Enjoy the feeling of relaxation as the muscles of your right arm give up their hold.... Feel the relaxation flowing into your hand... Let all the tension drain out of each finger tip and flow away.... the relaxation spreads to your thumb... index finger.... middle finger... ring finger... and little finger....

Feel the relaxation flowing down your left arm... Let the muscles of the left upper arm relax.... Relax your elbow.... lower arm.... and wrist....

Enjoy the feeling of relaxation you are experiencing.

Let the tension melt away.... imagine the tension flowing right out of your finger tips... Allow your left hand to relax completely.... relax your thumb... index finger.... middle finger... ring finger... and little finger....

Both of your arms are now totally relaxed... allow them to be free and limp... pleasantly relaxed...

Enjoy the feeling of relaxation you are experiencing...

Allow the feeling of relaxation to continue to your chest and stomach....feel the relaxation there... becoming deeper with each breath....

Now turn your attention to your upper back... Feel the relaxation flow down your spine... Let all the muscles give up their hold.... relax your upper back... middle and lower back.... allow your back to relax completely..... Feel the relaxation in your whole upper body

Relax more deeply with each breath.... more and more relaxed.... deeply relaxed and calm....

Let your hip muscles relax.... Relax all the way from your buttocks (bottom), down the back of your thighs... relax the muscles on the front of your thighs...Feel the relaxation in your upper legs moving down to your knees... your calves and shins.... your ankles.... and your feet.... allow all the muscles to relax and go limp....

Allow any last bits of tension to flow right out of the soles of your feet....Feel the relaxation flowing through your body... From the top of your head... down to the bottoms of your feet.... become more relaxed with each breath.... enjoy the feeling of total relaxation.....

You are now as relaxed as you want to be.... Experience the feeling of deep relaxation... enjoy the feeling.... relaxed.... calm..... at peace

Focus on the feeling of relaxation throughout your body.... Notice your breathing.... Your relaxed muscles.... Your calm thoughts... Memorize this feeling so you can re-create this relaxed state whenever you wish....

Enjoy relaxing for a few moments more....

When you are ready to return to your day, reawaken your body slowly... gently move your muscles... roll your shoulders slowly forward.... then slowly backward.... lean your head gently to the left... return to centre.... lean your head gently to the right... turn your head...

Wriggle your fingers and toes....

Gently open your eyes.... Feeling alert... calm.... and full of energy.

Short relaxation:

Deep breathing not only helps to cure anxiety and stress, it also triggers relaxation. Here's how to breathe deeply.

Breathe in slowly to the count of four (count slowly; to the pace of one-one-thousand, two-one-thousand...).

Pause to the count of three.

Breathe out slowly to the count of five.

The breathing process goes like this:

Inhale... two, three, four...pause...two, three....exhale...two, three, four five....

Inhale... two, three, four...pause...two, three....exhale...two, three, four five....

Repeat for a minute or two.

Action Plan Form – Stress Management

Think about one thing that is causing you stress. Use this action plan form to come up with a plan of how to manage your stress this week.

Be sure your action plan includes:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

How confident are you that you can complete this action plan?

Not at all											Totally
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise Diary

Use this exercise diary to keep track of your exercise goals and activities.

Start off by writing down your goal.

Write down here what you want to be able to do: _____

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

	Exercise Planned	Exercise I did...	How did I feel? Do you need to change anything?
e.g.	20 mins in a.m. after breakfast and in p.m. after supper		Very tired by the second session, I'm going to cut it down to morning only for this week.
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 4: Pain

Many people living with HIV/AIDS experience pain and it is very often the symptom which bothers them most.



We know this from lots of scientific studies conducted across South Africa, Africa and the rest of the world. There can be many reasons for someone living with HIV/AIDS to have pain. The pain may be caused by the virus, or the pain may be caused by the medicines used to keep you healthy or the pain might be for a reason that has nothing to do with HIV/AIDS.

The pain may be caused by the disease, for example if the virus damages nerves you may feel pain. Pain may also be caused or made worse by tense muscles. When something hurts we tend to make our muscles tense to try and protect ourselves. Pain may also be caused by weak muscles or stiff joints. People with HIV/AIDS often become less active and their muscles and joints get weak and stiff. Then when they do use their muscles and joints these can hurt because they haven't been used for a long time and they aren't used to it. Finally stress, fear, anxiety and depression can cause pain and



make pain worse. We know from research that when you are in pain your brain is very active. If you are also stressed, or afraid, worried or anxious, or depressed, your brain becomes even more active. This does not mean that your pain is not real, what it does mean is that activity in your brain can cause pain or if you are already in pain, it can make it worse.

To properly treat pain we have to make sure that we check and treat all the possible causes of pain.

Checking the cause of pain

If you develop a new pain which you have not felt before it is important for you to pay attention to it. Pain is your body's way of getting your attention that something might be wrong. It does not always mean that something is wrong; it may just be a warning. It's like when you put your hand on something hot, it hurts and you pull your hand away. Often your hand is not burnt, but it was painful, the pain got your attention quickly and you moved your hand before you got burnt.

If you have not felt the pain before it is important for a doctor or a nurse to examine you to find the cause of the pain. If they find the cause of the pain they may give you medication to treat the cause. If you have TB you might have pain, the doctors or nurses might give you medicine for the TB to treat the cause of the pain. They should also give you medicine for the pain itself. If they forget to give you pain medicine you must ask for it. Sometimes you may only be given pain tablets for a few days, if you know your pain lasts for the whole month you must tell the nurse or doctor this and they should give you medicine for the whole month.



In up to one third of people with HIV/AIDS who have pain, the doctors or nurses might not find any reason or cause for the pain. This does not mean that the pain is not real or that it should not be treated. If they do not find a clear cause for your pain they should still give you pain medicine.

What can you do for pain?

There are lots of things you can do for yourself to help manage your pain. Because we know that the brain is very involved when someone is in pain, we also know that understanding your illness, being a self-manager who understands about their treatment and, having support can help manage your pain. We are now going to talk about different things that you can do to help decrease pain.

Exercise

Doing any kind of exercise, stretching, strengthening or endurance exercise can all help to decrease pain. We also know that people who exercise regularly have less pain.

Relaxation

Managing stress and doing relaxation exercises also helps to decrease pain. This works because it decreases the activity in the brain. We also know that if you do regular relaxation it can help you to sleep better. People with pain often find that the pain is worse at night and that it is difficult to sleep. Bad sleep can also make pain worse. Doing relaxation and being able to sleep better will help to reduce the pain and help to prevent it getting worse. You can also help your pain by managing stress and anxiety. You can do this by talking to people and getting support, either from a nurse, a counsellor or a support group.



Heat

If your pain is being caused by tense muscles then heat can help to decrease it. You can warm up the muscles by having a warm bath or shower with the water on the affected area. If you cannot have a hot bath or shower, then keeping the muscles warm with clothes or a blanket can also help. There is one time when you should not use heat for pain. If you touch the painful area and it is already hot, this means it is inflamed and you should not make it hotter. If the area is infected or the skin is damaged then it is also better not to make it hot. In both these situations, it is better to use cold.

Cold

Cold is a very good way to treat pain. When we make nerves that send messages warning us about damage cold, they slow down and send fewer messages. This means that we feel less pain. If you have a freezer then you could use a packet of ice or of frozen vegetables on the painful area. Only leave it on your skin for 10 minutes at a time. If you do not have a freezer then putting a damp cloth on your skin (if you have a fridge then use water from the fridge) will also work well.



Massage

Self-massage is a very simple but very good way to treat pain. You may have even been doing it without realising this is what you were doing. If you have ever rubbed a painful arm or leg then you have done some self-massage. You can use a simple cream or baby powder to do massage. Gentle rubbing of a painful area can relieve pain a lot. BUT, as with heat, if the painful area is hot or infected then it is better not to rub it. Rather use cold. If you have pain *and* the painful area is hot, red and swollen this may be a sign of an infection. If you have been using ice on this for a day and it is not getting better, visit the clinic.

Support

As we said before, when we feel pain, our brains become very busy. We often worry about the pain, we may feel scared about what is causing the pain or what the pain means (we often talk about this as stress – “I feel so stressed!”). We might wonder what we have done to be getting pain. The fear and worry we feel when we have pain can make the pain worse. This is why support is so important to help pain. It is helpful to talk to people that we trust about how we feel. It is also helpful to be reassured by a nurse or doctor about what is causing our pain. It may be that worrying about HIV is making your muscles tense and this is causing your neck to pain or causing headaches. It helps if the doctor or nurse can reassure you that the pain is caused by stress. This does not mean that you are making it up or that it is not real! It means that there is something you can do to help the pain. Talking to people, doing exercise and relaxation all help to manage stress and this will help the pain.



Medicine

If you have medicine to help your pain it is important that you take it regularly. Do not wait for the pain to start before you take the medicine, if you wait it will not work as well. If the doctor or nurse has told you to take the medicine several times a day then it is important that you do this, even if you are not feeling any pain at the time; not feeling pain means that the medicine is working. Do not wait for the pain to come back again before taking another pill, it won't work as well. If your medicines are not helping the pain then you must go back to the nurse or doctor. You might need stronger medicine or you might need to take two different kinds of medicine at the same time.



Common medicines used to treat pain are:



- Paracetamol (panado, dolorol, painamol, painstop) is a very good, very effective and safe medicine for pain. It is important not to take more than 10 tablets per day.
- Aspirin (disprin) is also very good but some people need to be careful with this medicine. If you use it for a long time you need to be careful of side-effects like ulcers, asthma or kidney problems.
- Anti-inflammatories like indomethacin (indocid), diclofenac (voltaren or panamor) or ibuprofen (brufen or inza) are good if your pain is being caused by inflamed muscles or joints. These must be taken with food. These can also cause side-effects like ulcers.
- Paracetamol and Codeine is stronger than paracetamol on its own. If you have been using paracetamol on its own and taking it as the nurse or doctor told you but your pain is not getting better they may give you paracetamol with codeine.
- Dextropropoxyphene (Doloxene) is a stronger pain medicine. This medicine is not easily available at clinics and the doctor or nurse would need to arrange for you to get it.
- Codeine phosphate is much stronger and can only be prescribed by a doctor. This medicine can make you sleepy and can cause constipation.
- Morphine is the strongest pain medicine. It can be taken up to 5 times a day. It also has to be prescribed by a doctor. If you are prescribed morphine make sure the doctor also gives you a laxative to prevent constipation.

Remember that the most important thing about the pain medicines is to take them before the pain starts or as soon as the pain starts. Don't wait for the pain to become severe before you take the pain medicine. It won't work nearly as well.

Pain

- Pain is one of the most common symptoms people living with HIV/AIDS experience
- Pain can be caused by the virus, by tense muscles, by weak muscles and stiff joints.
- Pain can be caused by and made worse by stress and worry
- Exercise, relaxation, cold, heat and massage are all good ways of treating pain
- Medication for pain works best if it is taken regularly and before the pain becomes very bad.

Action Plan Form - Pain

Think about one pain which you commonly experience. Use this action plan form to develop a plan of how you are going to manage that pain.

Be sure your action plan includes:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

How confident are you that you can complete this action plan?

Not at all										Totally	
confident	1	2	3	4	5	6	7	8	9	10	confident

Keep a record of how you did:

	I Plan to.....	I did.....
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise Diary

Use this exercise diary to keep track of your progress with your exercise goal which you set in week one.

Start off by writing down your goal.

Write down here what you want to be able to do: _____

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

	Exercise Planned	Exercise I did...	How did I feel? Do you need to change anything?
e.g.	<i>20 mins in a.m. after breakfast and in p.m. after supper</i>		<i>Very tired by the second session, I'm going to cut it down to morning only for this week.</i>
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			

Week 5: Eating Well

Eating well is important for everyone, eating well helps keep you healthy and if you are sick, either with HIV or any other illness, eating well is important to help you feel better. Treatment is not just taking anti-retroviral medicines; it is taking anti-retroviral medicines and eating well. When you are living with HIV, your body burns more energy than someone who does not have the virus. The virus makes your body use 10% more energy even when you are feeling well and between 20% and 30% more energy when you are feeling sick. This means that you have to eat more just to keep your weight the same. Losing weight is one of the most common symptoms of HIV. People with HIV mostly lose muscle weight, which makes them thin and also makes them weaker. So, how do you stop losing weight, or if you have already lost weight, how do you help your body recover? It is not difficult or complicated to eat well to stay healthy. We are going to discuss some simple steps to follow to eat well.



What should I eat?

Our bodies need energy to be able to do all the things we need to do every day. This energy comes from food and the best source of energy is food which has complex sugars in it. Complex sugars are not sweet, they are foods that many of us eat every day – the starch foods. Starchy foods like bread, pap, rice, potato and mngqusho



are high energy foods (complex sugars). When our bodies run out of this high energy food, it will start to use energy stored in the body. Before you had HIV, your body would use fat to provide energy. But, now with the virus your body uses energy stored in muscles – protein energy. If you do not eat enough, your body will run out of complex sugars to give it energy and will start using protein from the muscles. This means that you will start to lose muscle and not fat – we call this wasting. If you eat foods with complex sugars (starchy foods - energy foods) regularly you can stop this happening. If you have already lost weight because of the virus, then you need to eat food with protein to help your muscles recover. Try to make sure you have high energy food (starchy food) with every meal.

One of the important steps for eating well is to eat small meals or snacks often through the day. It is best to try and eat 3 meals a day and have another 2 snacks a day. This means that we should eat 5 times a day; these meals do not all need to be big meals, a snack might be some fruit, nuts or sour milk. By eating 5 times a day we can make sure that we do not run out of energy. When we run out of energy, our bodies have to work harder, if we have pain the pain will get worse, if we are tired we will become more tired, if we are feeling sad we will feel sadder when we run out of energy and if you are trying to concentrate then it is harder to concentrate when you run out of energy. Also, if you have HIV and you run out of energy your body starts to use the protein in

muscle and you start to develop wasting. For these reasons it is important to eat at least 3 times a day and better to eat 5 times a day.

There is no single food which is good or bad. It is important to eat a variety of foods. We will now talk about the different food groups which we should be eating from every day.

Starchy Foods (also called carbohydrates or complex sugars)

Bread-Potatoes-Pasta-Rice-Sweet Potatoes -Samp-Mealies-Sorghum-Pap-Porridge-Cereals

We need to have enough energy, so the starchy foods (complex sugars) should be the main part of our diets. Starchy foods should make up the main portion of all meals. Starchy foods can give us energy for a long time. In the shops or in magazines you might see food labelled “low GI”. “Low GI” foods are starchy foods which give us energy for a very long time compared to other starchy foods which are “high GI” which don’t give energy for as long. Both these kinds of starchy food are important for people living with HIV.

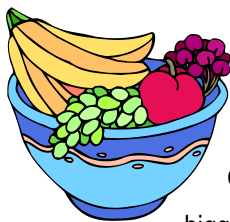


Fruits and Vegetables

Spinach-Morogo-Pumpkin-Green Peppers-Lettuce-Beans-Squash-Carrots-Tomatoes

Peaches-Apricots-Oranges-Naartjies-Avocados-Paw Paw-Mango-Guavas-Watermelon

The second most important groups of food which we need are the fruits and vegetables. We should eat at least one fruit and one vegetable with every meal and aim to have at least 7 portions of fruits and vegetables every day. Fruits and vegetables supply vitamins and substances which are important for keeping the immune system strong. Try to eat a variety of fruits and vegetables and include vegetables which are yellow, orange, red or dark green in colour.

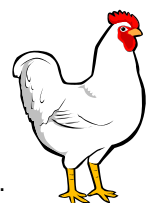


These fruits and vegetables contain a vitamin (vitamin A) which helps the lining of the stomach. Citrus fruits like oranges, lemons, grapefruit and naartjies are also important as they contain another vitamin (vitamin C) which helps the immune system to work. You can see in the picture below that the starchy foods and fruits and vegetables are the biggest sections of food.

Protein

Beef-Pork-Chicken-Fish-Mutton-Lamb-Eggs-Milk products-Beans-Grains-Nuts

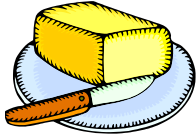
People living with HIV need to eat protein every day. As we said before, this is important for your muscles and to help prevent weight loss. Protein is found in meats and milk based foods. You can also get protein from dried beans, peas, lentils, peanuts or soya. These foods can be a very economical way of getting enough protein, they are often much cheaper than meat or milk products.



Fats and oils

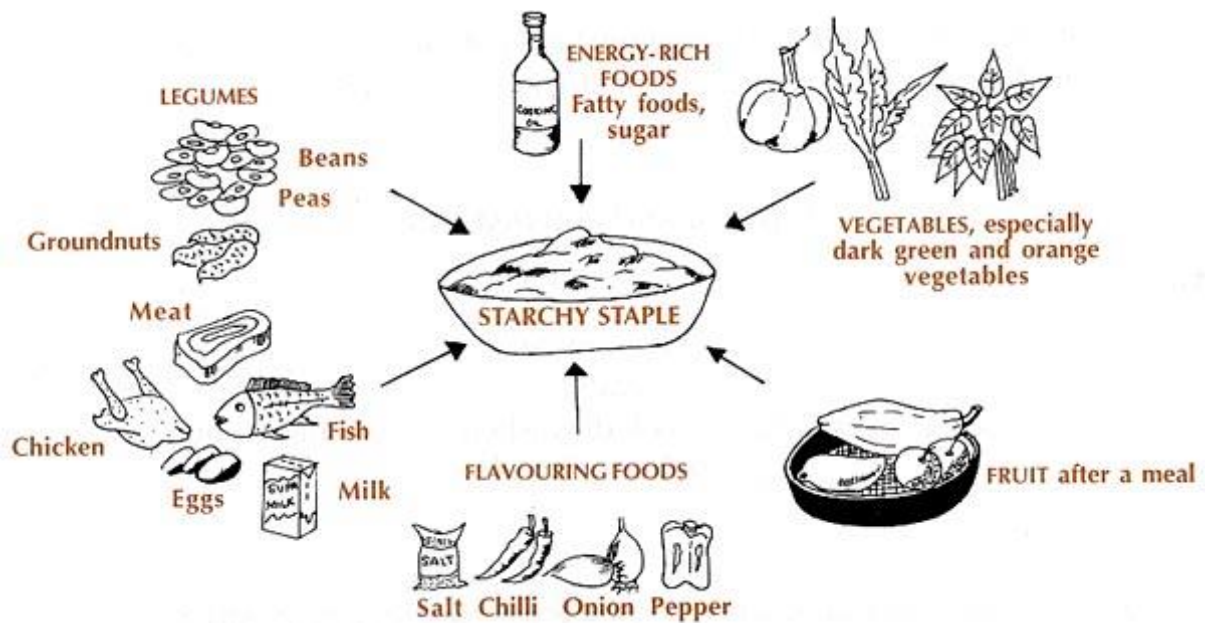
Butter-Lard-Margarine-Cooking oils-Cream-Mayonnaise

Fats and oils are also an important part of a healthy diet. These foods provide energy, like the starchy foods. This does not mean you can eat as much as you like of these foods, but they should make up a portion of your diet. These foods can be used to increase your weight if you have been sick with an infection and lost weight.



How do I put it all together?

A balanced way of eating is for each meal to include two portions of starch + one portion of vegetables + one portion of fruit + one portion of protein. The fat portion of the food is included as part of the cooking (if you use oil) or if you put butter or oil on your food.



A balanced meal

“I find it hard to eat well!”

Now that you know what you should be eating let's talk about why people living with HIV may be struggling to eat enough. The reasons for not eating enough could be that they do not want to eat because they just don't feel hungry or because they are too tired to eat or they are too worried to eat or they feel like they will vomit if they eat, or they have diarrhoea or they have sores in their mouth which hurt when they eat or food just doesn't taste good any more. The next section gives ideas on ways to manage these problems.

“I'm not hungry”

On the days when you feel like eating, make sure you eat well to make up for days when you might not be eating so well. On the days when you do not feel like eating try to eat small meals more often, maybe 6 times a day. Eat in a relaxing place, maybe with a friend. Keep small snacks with you in your bag or next to your bed so that if you wake up or suddenly feel hungry you can eat straight away. Make sure these snacks have lots of energy in them (are complex sugars). Make sure you have your favourite foods to eat, even if it's just a little bit it helps.

“I get full too quickly”

You might be trying to get all your food at one meal. Try to eat five or six times a day. When you do eat, make sure its food with lots of energy and protein. Don't eat foods without energy first and then feel too full for the important foods.

“Food doesn't taste so good”

Infections in the mouth or medicines can change the way food tastes. Sometimes you may have a bitter taste or a taste of metal in your mouth. If you have thrush, ask your doctor for medicine for this. You can also rinse your mouth with a mixture of 1 teaspoon of baking soda in a glass of water. DO NOT swallow this, rinse your mouth and spit it out. Try cleaning your teeth and your tongue before you eat. If you have a taste of metal in your mouth, try to drink orange juice or another tart drink.



“Eating makes me want to vomit”

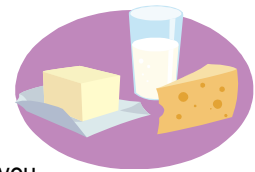
Wanting to vomit when you eat can be because of an infection or a side effect of the medication. Eating smaller meals helps (5 or 6 meals a day) – it is important to know that nausea or the feeling that you are going to vomit is often worse when your stomach is empty. Food with lots of spices or fats and food or drink with caffeine can irritate your stomach and make you feel sick. Salty and dry food might help (bread or crackers). If the smell of food makes you feel sick, ask someone else to cook, and also make sure there is lots of fresh air where the cooking is being done so that the smell clears quickly. Don't eat your favourite foods when you feel sick, you don't want to start thinking that your favourite foods make you feel sick. If you think your medicine is making you feel sick, ask your doctor or pharmacist about the best time to take the medicines which might help. You can also ask your doctor for medicine which will help to stop the feeling of nausea.

“I have diarrhoea”

Diarrhoea can be caused by the virus, by the medicines or by stress or other infections. When you have diarrhoea, your body is not getting the food that it needs, even if you are eating it, your body cannot absorb it. When you have diarrhoea, your body is also not getting enough fluids. You need to make sure you are getting enough liquid when you have diarrhoea to make sure that you don't get dehydrated. Go to the section on managing symptoms of HIV/AIDS for more information on how to manage diarrhoea. Remember, if you have diarrhoea for more than a week, you must go to your clinic for treatment.

“I feel sick if I eat dairy products”

Some people living with HIV find that drinking milk or eating milk products makes them feel sick. This is because the virus can affect a chemical in your intestine which you need to absorb milk. If this chemical is not present, you may feel bloated or get diarrhoea after eating milk products. This is called lactose intolerance. If this is happening to you, then you need to avoid eating milk products. Sometimes this reaction will get better; you might find that in a few months you could try a milk product again and not have the same reaction. This would mean that your body now has enough of the chemical it needs and you can resume eating milk products.



“My mouth is dry / I have sores in my mouth / chewing and swallowing hurts”

A dry mouth might be a side effect of medications. Sores and pain in the mouth can be from infections. You can help this by avoiding smoking and drinking alcohol as these irritate your mouth and throat. Eat softer food, if you mash your food or make soup as this will be easier to swallow. Try not to eat food with a lot of spices or drink fizzy drinks if your mouth is sore. These can make your mouth burn more. Eating cold food like ice cream or sucking on an ice block can help to numb your mouth. If your mouth is sore, try to drink through a straw. Rinse your mouth often and keep a bottle of water next to your bed so that you can rinse your mouth during the night.

Managing Eating Problems

- Try to eat at least 5 times a day – 3 meals and 2 snacks.
- Eat energy food first.
- Keep snacks with you to eat as soon as you feel hungry.
- Drink 6 glasses of juice and water a day.
- Drink rehydration fluid after every bout of diarrhoea.

Now that we have discussed how we should be eating and ways of managing eating problems, let's look at how to keep our food safe.

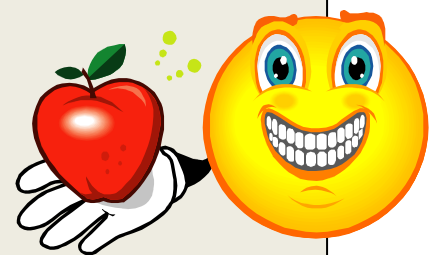
How do I keep my food safe?

If we don't pay attention to our food, where we get it from, how we store it and how we prepare and cook it, the food may become contaminated and make us sick. This is very important for the person living with HIV because you are more vulnerable to illness. There are simple ways to keep your food safe.



Storing and preparing food safely

- Read food labels carefully when you are shopping for food. Look for the “sell-by” and the “use-by” dates. Do not buy them if the “sell-by” date has already passed, do not buy if you are not sure that you will eat it before the “use-by” date.
- Don't buy food if the packaging is damaged
- Storing food properly is important to keep it safe. Food that you buy from the fridge or freezer section of a shop needs to be put into a fridge or freezer as soon as possible unless you are going to cook or eat it straight away.
- Write on the packages of food the date you bought them so that you can keep track of how long you have had it. Remember food that can make you sick doesn't always look or smell bad.
- If you want to keep leftover food, store it in a container with a tight lid and put it into a fridge or freezer immediately.
- If you have leftovers in the fridge you must eat them within 2 days. Leftovers that have been in the fridge for more than 2 days **MUST** be thrown away - even if they look and smell OK!
- Always wash your hands before preparing food. Wash your hands again after handling any raw food.
- Wash up all your cutlery and crockery in **HOT** soapy water.
- If you have eaten food that has made you sick it is important that you clean all equipment and surfaces in the kitchen which that food might have touched. You can clean it using a mixture of 1 tablespoon of bleach in a litre of water.
- Never eat raw meat, chicken or fish of any kind.
- Make sure all meat is well cooked – no red meat of any kind.
- When you buy eggs make sure none have cracked shells. Keep them cold
- Never eat any dish with raw eggs
- Use only pasteurized milk and milk products
- Wash all fruit and vegetables
- Keep fruit and vegetables in the fridge



Action Plan Form

Think about your eating habits. Use this form to come up with a plan to improve **one** thing about your nutrition.

Be sure your action plan includes:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

How confident are you that you can complete this action plan?

Not at all												Totally
confident	1	2	3	4	5	6	7	8	9	10	confident	

Keep a record of how you did:

	I Plan to.....	I did.....
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Exercise Diary

Keep using the exercise diary to keep track of your exercise goals from week one. You may want to start increasing your exercise plan.

Start off by writing down your goal.

Write down here what you want to be able to do: _____

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

What you want to do

How much you are going to do

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How many days a week you are going to do it



For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)

_____ (*how much*)

_____ (*when*)

_____ (*how many?*)

	Exercise Planned	Exercise I did...	How did I feel? Do you need to change anything?
e.g.	20 mins in a.m. after breakfast and in p.m. after supper		Very tired by the second session, I'm going to cut it down to morning only for this week.
Monday			
Tuesday			
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Friday			

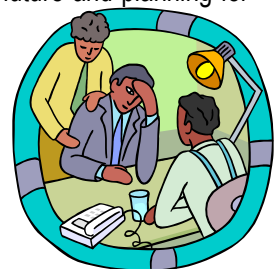
Week 6: Continuing as a Successful Self-Manager

Over the last six weeks you have learnt many skills which will help you to live positively with your condition. Research tells us that people living with any chronic disease who follow these steps have better quality of life, have fewer sick days and have better disease control. This is true for people living with high blood pressure, HIV/AIDS, cancer or depression. You have learnt how to be a positive self-manager by being able to solve problems and set goals for yourself so that you can move forward with your life. You have learnt about the importance of exercise. How exercise can make you feel better, what exercises you should do and you have been doing those exercises too! You have learnt about the common symptoms that trouble people living with HIV and you have learnt how to manage these symptoms. You have learnt about pain, what might be causing pain and how to treat and manage any pain you may have. You have learnt about food and eating well and how to make sure that your food is safe. With all of these you have also had the chance to practice doing things differently and to think about how this has made you feel.

Action Planning for the Future

Now it is time to think about the future. People with long term illnesses often worry about what will happen if they get very sick, how they will manage their lives; how they will they look after themselves or their families. Worrying about these things can also make people feel sad, angry or depressed and helpless. These emotions may make everything feel even more difficult than they are. By working through this book you have already started to deal with these emotions. You have increased your knowledge and this is one of the main ways that we manage fear. If we are afraid of something, knowing more about it helps us to tackle the fear. If you know more about it, you can make a plan around it and making a plan helps us to get a sense of control over the very thing that we are afraid of.

Planning for the future means thinking about the things that might happen to you in the future and planning for them. You may never ever need to use the plan as the things that you worry about may not happen, but, having a plan will help you to worry less about these things and stay in control should they happen. You can use the action planning forms you have been using in this workbook to think about the things which worry you about the future. You can then start making a plan about what you want to do if these things happen. If you are not sure about making a plan, you may want to talk to different people who might be able to help you with this.



Step 1:

To be able to plan for the future, you need to decide *what* it is that you are worried about happening. This can be the hardest step to think about. For example you might be feeling very sad and depressed. First you need to think about why you are feeling that way. It might be that you are worried about not being able to look after your family if you become ill, or you may be worried about making someone else ill, or you may be worried about not being able to look after yourself, or you may be worried about dying. Once you have identified what it is that worries you and makes you feel sad, depressed, angry or afraid then you can start to make a plan to deal with it. This will help you to feel less sad, depressed, angry or afraid.

Write down here some of the things that might happen in the future that you worry about:

1) _____

2) _____

3) _____



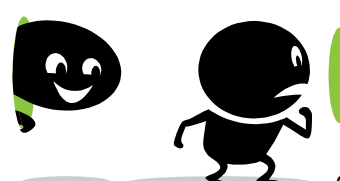
Step 2:

Now that you have identified some of the things which worry you, you can start to think about different ways to manage these things. If you were worried about becoming ill and not being able to look after yourself, write down a list of things that you would need help with. Then write down who you could ask to help you with those things. The people who can help might be family, friends, social workers, counsellors, nurses, physiotherapists, occupational therapists or doctors. If you are not sure who could help you, you may want to talk to someone you trust to help you identify who could help.

Write down here three different things you could do to help plan for the things in the future that you worry about:

1) _____
2) _____
3) _____

There are many organisations and people who you can approach for help in planning for the future. These organisations include the Treatment Action Campaign (TAC), the Family and Marriage Society of South Africa (FAMSA), your church, the AIDS consortium; the Aids Law Project (ALP), the National Association of People living with HIV/AIDS (NAPWA) as well as the health care practitioners at your local clinic. The contact details for these organisations are included at the end of this section.



Once you have completed Step 2 and written down three different things you could do to help plan for the things in the future that you worry about, choose the one which seems to suit you the best (this might be one which is easier or is cheaper or you know has worked for someone else). Now use this action plan form to work out what you will do if the thing which you worry about happening should happen. You can use this method to plan for any of the things which worry you.

Action Plan Form for Future Worries

I am worried that in the future I will not be able to:

My plan to manage this if it happens is to:

(what, who, how, when?)



How confident are you that you can complete this action plan? (remember you are aiming for 7 out of 10 on the confidence line)

Not at all										Totally	
confident	1	2	3	4	5	6	7	8	9	10	confident

Useful Organisations:

Treatment Action Campaign (TAC) (<http://www.tac.org.za>)

Cape Town (021) 422-1700

Khayalitsha (021) 364-5489

Family and Marriage Society of South Africa (FAMSA) (<http://www.famsa.org.za>)

Cape Town (021) 447-7951

Khayalitsha (021) 361-9098

AIDS consortium (<http://www.aidsconsortium.org.za/>)

National office (011) 403-0265

Aids Law Project (ALP) (<http://alp.immedia.co.za/>)

National office (011) 356-4100

National Association of People living with HIV/AIDS (NAPWA) (<http://www.napwa.org.za/>)

Cape Town (021) 425-6860

Additional Reading

The information in this workbook is based on several sources of information. If you would like to read more on any of these topics we suggest you explore these:

Living Well with HIV & AIDS; Gifford A.L.; Lorig K; Laurent D; Gonzalez V (3rd edition) Bull Publishing Company, Boulder Colorado 2005

Self-management of Long-term Health Conditions: A handbook for people with chronic disease. Expert Patients Programme Community Interest Company . Bull Publishing Company, Boulder Colorado 2007

Manage your pain. Nicholas M, Molloy A, Tonkin L, Beeston L ABC Books, Sydney 2000

HIV in our lives: a book of information sheets for clinics. Treatment Action Campaign, Cape Town, 2007

Action Plan Form

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How much you are going to do

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How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

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Tuesday			
Wednesday			
Thursday			
Friday			

Exercise Diary

Start off by writing down your goal.

Write down here what you want to be able to do: _____

Now, what do you want to be able to do this week which will help you to reach your goal?

Remember from your action plan to include:

What you want to do

How much you are going to do

When you are going to do it

How many days a week you are going to do it

For example: This week, I will walk (*what*) around the block (*how much*) before lunch (*when*) three times (*how many*).

This week I will:

_____ (*what*)
 _____ (*how much*)
 _____ (*when*)
 _____ (*how many?*)

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