

PSYCHOSOCIAL WELLBEING SERIES

Mam's

Tracking your Health

A Guide to Creating a Tracing Book



Psychosocial Wellbeing For All Children

REPSSI is a regional capacity building organisation working in Southern and Eastern Africa to enhance the psychosocial wellbeing of all children affected by HIV and AIDS, poverty and conflict.

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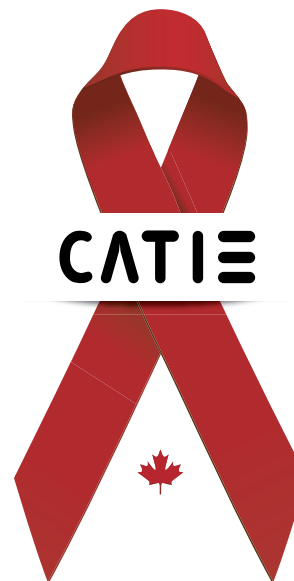
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Introduction

This manual is the second in a series called Body Maps:
Bringing Mind, Body and Community Together for Wellbeing.

The Body Mapping series consists of the following publications:

1. *Living with X: A Body Mapping journey in the time of HIV and AIDS*, Facilitators Guide, REPSSI, 2007.
2. *Tracking your Health: A Guide to Creating a Tracing Book*, REPSSI, CATIE, 2009.
3. *Understanding HIV Basics*, REPSSI, CATIE, 2009.

Acknowledgements and Contributions

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Tricia Smith is an Educator at CATIE, and is responsible for the management of the REPSSI-CATIE partnership and the treatment information aspects of this project and series.

REPSSI is a regional psychosocial capacity-building organization working in thirteen countries with over 200 partner organizations in East and Southern Africa. Our aim is to enhance the psychosocial well-being of children, families and communities affected by HIV/AIDS, poverty and conflict.

CATIE (Canadian AIDS Treatment Information Exchange) is a Canadian not-for-profit organization committed to improving the health and quality of life of all people living with HIV/AIDS in Canada. CATIE serves people living with HIV/AIDS and the people and organizations that support them by providing accessible, accurate, unbiased and timely HIV information. CATIE works in partnership with a network of other information providers to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.



Levels of Psychosocial Support (PSS)

5. Specialised Mental Health Services:

PSS is key in the areas of psychiatric, clinical psychological, and specialised traditional healer services, for individuals with clinical mental health diagnoses (potential to benefit only small numbers of the most severely affected individuals at any time).

4. Focused Support:

PSS is important for the special needs of children who are not coping, and who are exhibiting symptoms of distress (potential to affect and benefit hundreds but probably not thousands of more severely affected individuals at any time).

3. Family and Community Support:

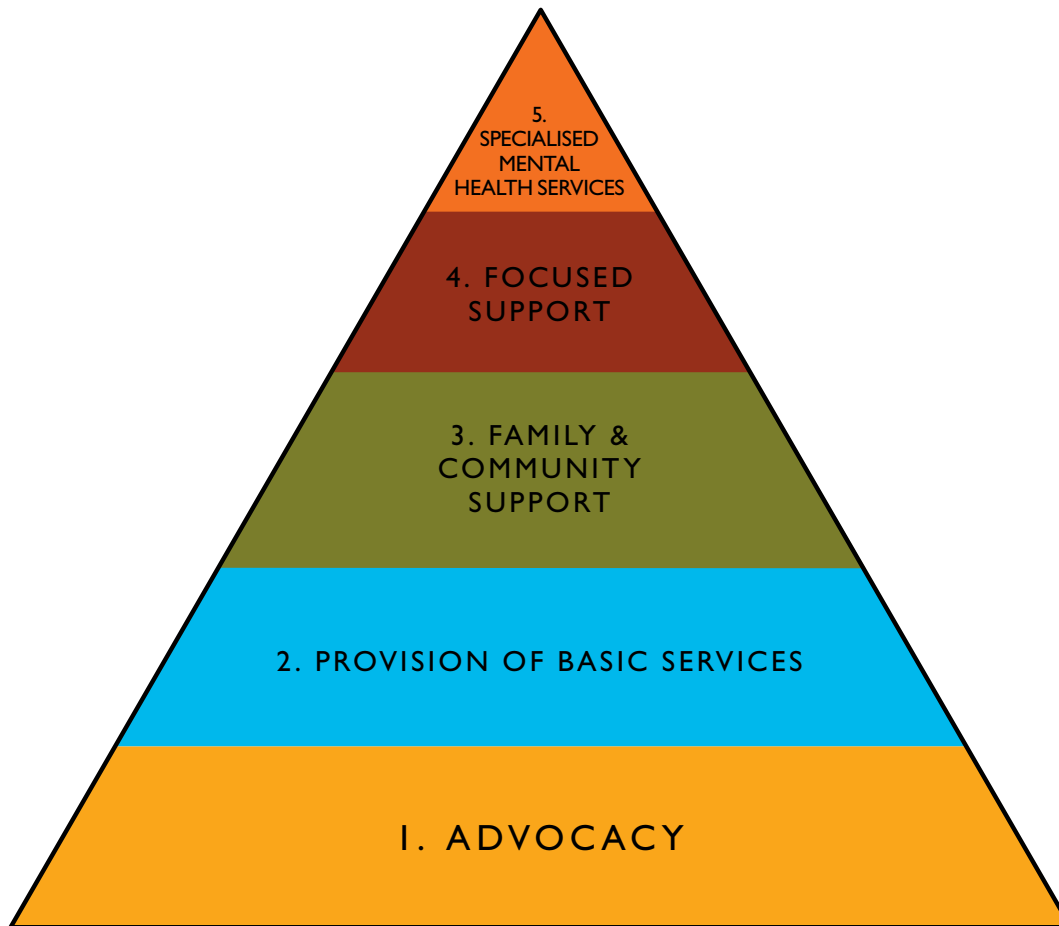
PSS involves everyday care and support provided by caregivers, friends, and community members (potential to affect and benefit thousands of individuals at any time, the most powerful and sustainable form of PSS).

2. Provision of Basic Services:

The provision of food, shelter, education, housing, health etc into which PSS needs to be mainstreamed (potential to affect and benefit millions of individuals at any time).

1. Advocacy:

PSS can influence policy and direct change to the social conditions that directly affect wellbeing (potential to affect and benefit millions of individuals).



Multi layered, integrated psychosocial support

Dear readers,

In relation to the pyramid on the previous page, Tracing Books explicitly strive to mainstream PSS into health services, in this case HIV treatment provided by clinics, hospitals and home based care.

Both REPSSI and CATIE are proud of this publication borne out of a fruitful collaboration between two geographically distant organizations; one being based in Southern and Eastern Africa and the other based in Canada. Both organizations however are united in their efforts to address HIV and AIDS and this approach exemplifies how the struggle against the pandemic can take the form of integrated, multi layered and mainstreamed tools, approaches and partnerships.

Ntuni

Noreen Huni
Executive Director REPSSI

Dear readers,

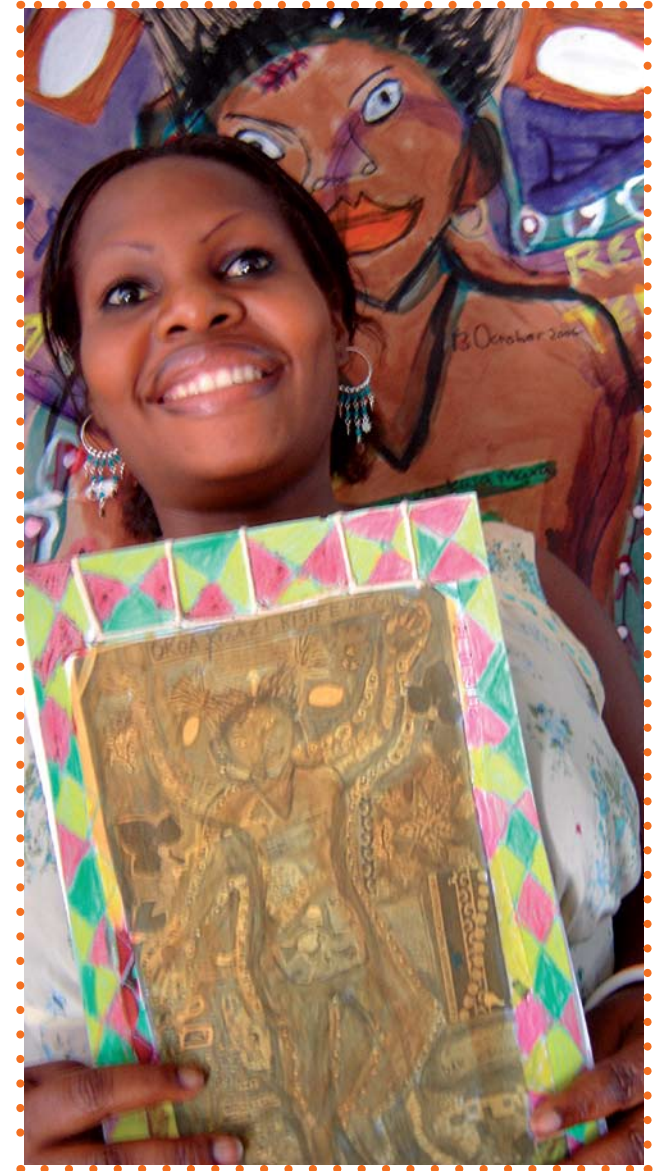
The opportunity to see the REPSSI – CATIE collaboration bear fruit has been a most worthwhile opportunity. From the first days of the partnership it has been most exciting to witness to see psychosocial support meeting bio-medicine in a community approach. The work between two very committed organizations has shown that even when distance separates us physically meaningful, innovative community-minded tools can still be developed and shared.

It is my hope that all who were involved in this work know the true value of their commitment. The information which lies in these pages has been borne out of a community model and has taken seriously the feedback from all those who have participated in Body Mapping, Tracing Book and Treatment Information workshops.

It is with great hope that this work sees a long and prosperous life. May all of you who use these manuals experience the strength of those who have made it happen.

Tricia Smith

Tricia Smith
Project Manager



Tracing Books

A Tracing Book is somewhat like a smaller version of a Body Map. A Body Map is a life sized tracing of a body combined with text and symbols. Via a detailed set of exercises a person has the opportunity to explore their own life journey. Body Maps have served many purposes including self-exploration, therapy (when done with a properly trained facilitator), and advocacy.

If you have had the opportunity to make a Body Map you will be able to see the similarities and the important differences between life sized maps and smaller, hand-held Tracing Books. If you have never made a Body Map you can still make a Tracing Book. It is a book that everyone can make and use throughout their lives.

We hope that you will use your Tracing Book to better understand your own health and to keep track of changes that you see or feel in your body. A Tracing Book can be kept just for you but we hope that you will one day choose to share it with others. It is a great tool to use when you want to communicate your health issues with your doctor or nurse. Sometimes we don't always have the words when we want to tell our doctor what is troubling us. With a Tracing Book you do not always need words. Rather you can draw symbols or mark on an outline of a body and use this tracing to help you remember and track ongoing changes in your health. You can also use a Tracing Book like a diary or journal and enter things that are important in your personal life.



There are other people you might wish to share your Tracing Book with. You might, for example want to use your Tracing Book as a way to speak with your children about HIV. Sometimes younger children become nervous of a parent's illness and need a way to better understand what is happening. You can use a Tracing Book to show your child that you are indeed strong and that you are able to manage your

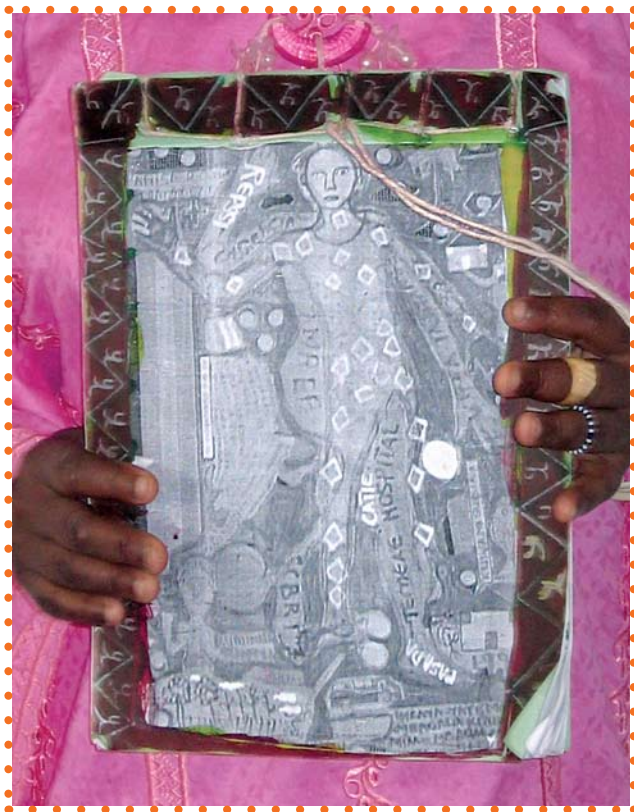
health with the help of your doctor and the other people who make up your health-care team. Even at times when you are not feeling well you can explain to your child what part of your body is giving you trouble and what your doctor has explained to you about your problem.

Some parents have used their Tracing Books to encourage their older children to get tested for HIV. They have shared the fears and hopes they have for their children and encouraged them to live a healthy life by knowing their HIV status.

A Tracing Book can also be used as a very important piece of information should you become ill. If you keep track of all your medications, appointments, and health issues in your Tracing Book, you can instruct your family to ensure that this book goes to a hospital with you should you ever become too sick to communicate your thoughts on your own.

A Tracing Book is unlike a larger Body Map in that things are always changing in your body and you keep track of these things week after week. For example, after one week, an infection on your leg might be recorded on your Body Map. By week 2, it might have gotten smaller or bigger and you make a note of this.

You might also have experienced changes in daily life that cannot be expressed as directly related to your physical health. For example, you may have experienced worry and



fear due to loss of a job or the inability to pay the rent for your accommodation. If you are entering this in your Tracing Book, you can use symbols to represent this worry. It is very important to acknowledge worry and anxiety because these things can have an overall affect on your general health. We know that people's CD4+ cell counts can decrease during times of stress so keeping track of stressful times can be helpful.

What can a tracing book be used for?

- Keeping track of medications and how and when you take them
- To share with your doctor any changes that have occurred since your last visit
- You can ask your doctor to make simple notes about your medications or symptoms in your tracing book. This way you will be able to refer to these notes once you return home
- You can use a Tracing Book to talk about side effects
- You can use a Tracing Book in conjunction with the HIV Treatment Information Basics Manual that is also a part of this series. Knowing what is happening in your body as a result of HIV and the medications you are taking can be very helpful.

Stress can also affect your ability to take your HIV medications on time and in the proper way. It is important to record any time when you have missed a dose. When sharing your book with your doctor he or she will be able to see how well you are managing your medication schedule and possibly give you other options should your current schedule not be working for you. The sharing of adherence, medication and side effects stories among support groups by using your Tracing Books, can also be important. Encouraging others to take their medications on time and in the right way, can be an important step to communicating just what can happen to your body when medications are not taken on schedule.

By making a Tracing Book, with each new page, you can begin to tell the story of your health both physically

and psychologically. As you move forward and become empowered to share your journey, you will see a story board of your life and hopefully feel in control of your body and the ups and downs that you live through each and every day.

“If you feel comfortable you can share your Tracing Book with your children, family, and friends so they can better understand what is happening with your health.”

How to make a Tracing Book

You don't need fancy or expensive materials to make a Tracing Book.

Here are some ideas for making a Tracing Book from materials you may have on hand.

- Take any old scrap paper or cardboard and cut it so that it forms a front and back cover for your book. Poke three holes in each piece of scrap paper or cardboard in order to form the spine of the book.
- Take as many other pieces of paper as you can find and poke three holes going down the side. These pages need only be blank on one side for your drawings and notes.
- Next thread some old yarn or string through the holes and also add the two cover pages to each end. Tie the yarn or string and now you have a basic book.

“You can also use a small exercise or note book to serve as your Tracing Book. You can glue one clean piece of paper to the front and back covers of the exercise book. This way you have a clean page to decorate for your cover. Remember that this book does not require costly materials. Your book will have a personality of its own once you decorate it.”



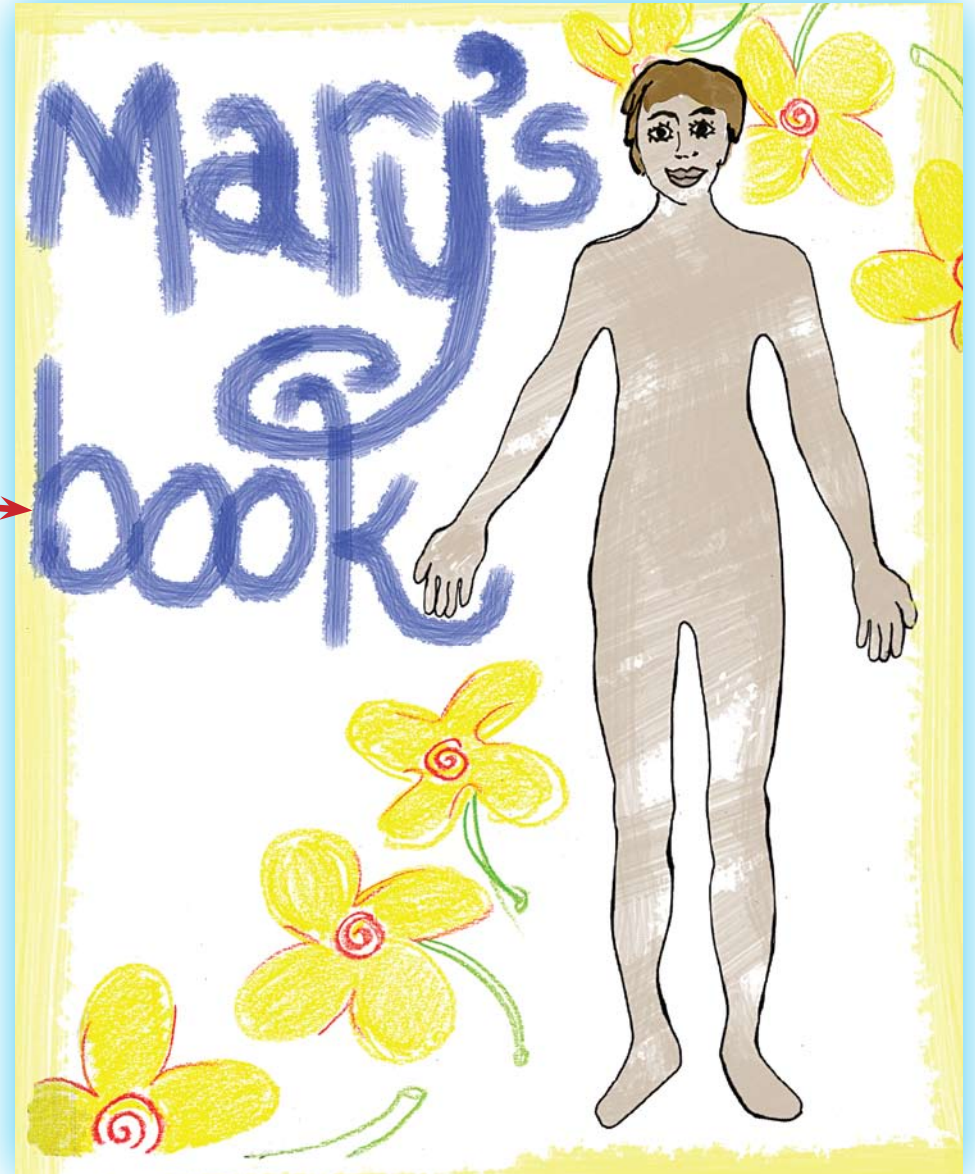
Decorating your cover

Let's get started.

This is your book so you can feel free to decorate it as you wish. Some people draw a simple outline of their body to represent how they will be drawing body tracings over the course of time. It is important, if you are comfortable doing so, to put your name on your cover in case your Tracing Book ever gets lost or misplaced.

This is just an example of a cover.

Perhaps you don't want a body tracing on the cover of your Tracing Book, in which case design any cover you want. You can draw symbols that are important to you, or images of things that represent who you are or how you are feeling.



Making Tracing Number One

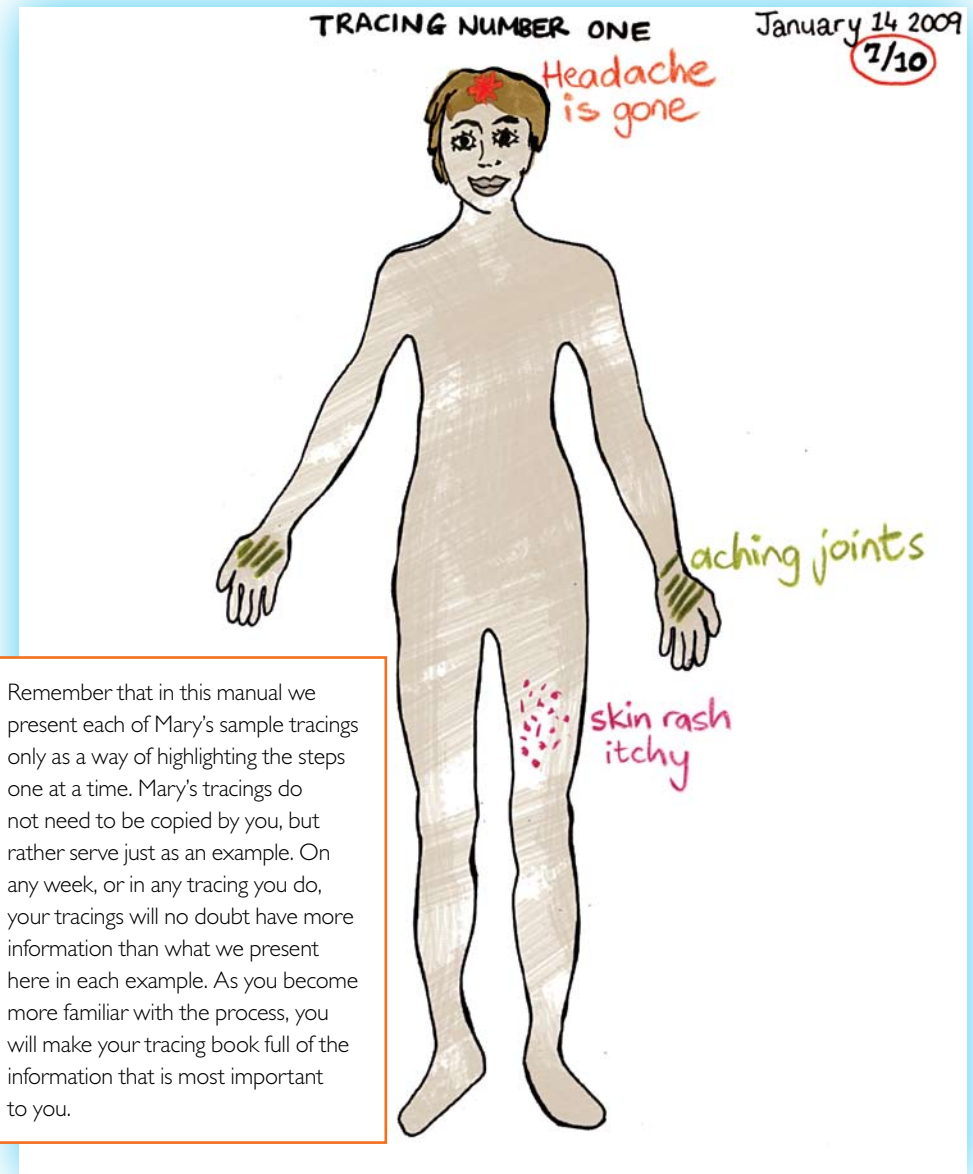
The following exercises from pages 8-13 guide you through the instructions involved in how to make a Tracing Book. If you follow these instructions you will understand a range of options that you can include for each tracing that you make after that. For those of you who have made a big Body Map, the difference between the two is that from now on with a Tracing Book we want you only to be thinking about things that can change over time. For example, a birthmark or old scar will probably stay the same for a long time so you do not need to put those things in your Tracing Book. However the TB in your lungs, or a persistent rash on your skin, might get better or worse over time. These would be good to include in your tracings.

Now let's begin. First of all, draw an outline of your body shape. Make it fill most of the page. You can show yourself as you are feeling right now. For example, your hands might be up in the air as your body jumps with energy, or your head and shoulders might be drooping. You can use color and shading to show things like excitement, hopefulness, fear, worry or even depression.

Once you have finished your body outline, fill in the date on the top right hand side of the page. Next to it, add the words: **Tracing Number One**. Under the date, using a scale of 1-10, choose a number that represents how you feel today. **1 = terrible and 10 = great**. So think of a number along this scale. For example if you feel pretty well, write "I feel 7 out of 10 today".

Next, think about the following:

- Where on or in your body do you feel better than last week? Mark the places and write a few simple words to represent what you mean. (In the example see "Headache is gone".)
- Where on or in your body do you feel pain or discomfort, or where have you noticed change in your body? (In the example see "aching joints" and "skin rash itchy".)



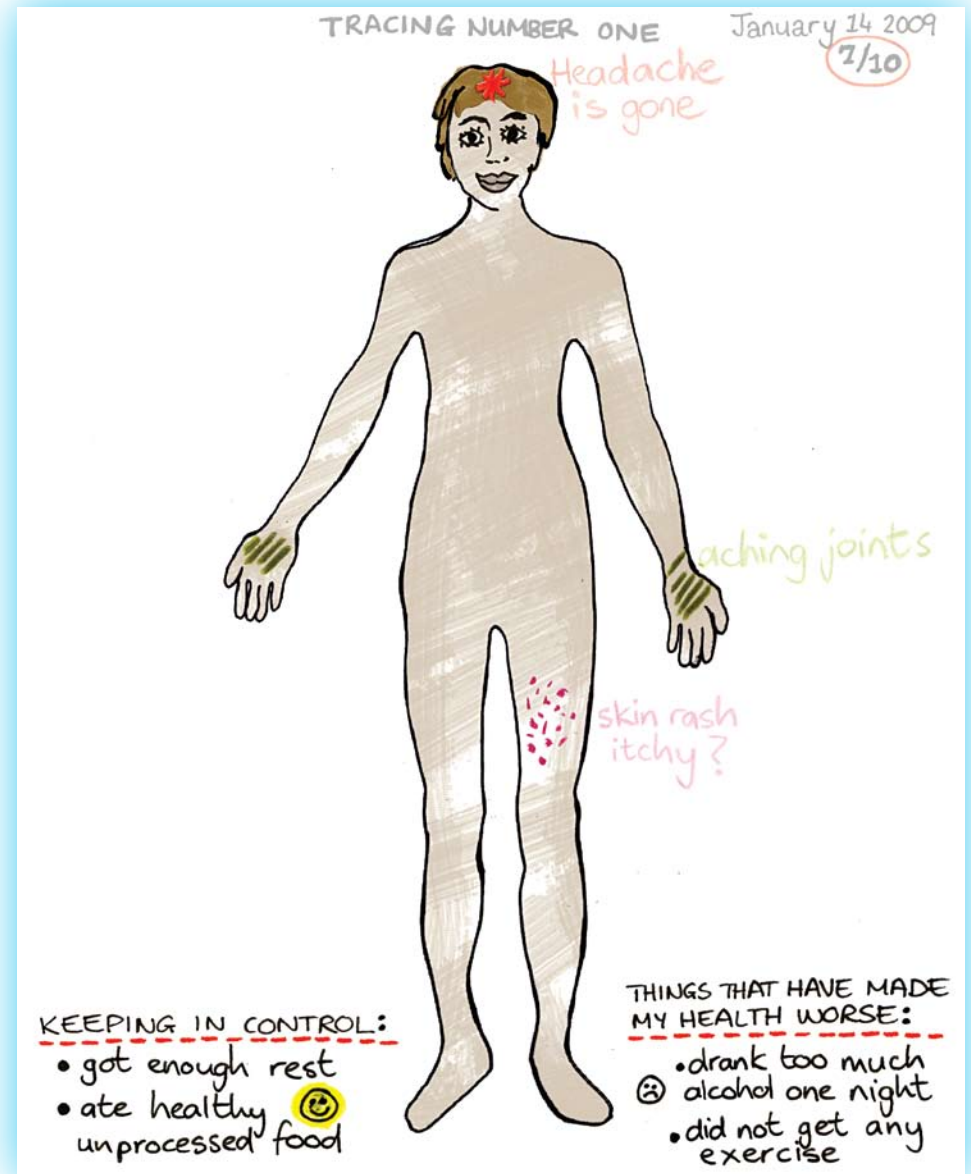
Your health over the past few days

Remember that this is the same tracing that you began on Page 8, but we are just adding some extra themes or prompts.

Next we want you to think about your health this week. Sometimes we feel like we are more in control of our health and sometimes it feels like our health issues control us.

- We want you to now think about things you have done recently to keep well and that make you feel like you have some degree of control over your health. For example, eating healthy food, taking your medicines, going to a support group or disclosing to a close family member can be ways in which you are taking control over your health.
- We also want you to think about things you have done over the past few days that may have **made your health worse**. For example smoking, drinking alcohol or having unsafe sex can be things that cause you to feel out of control.

You will see there is an additional chapter at the end of this book. It's called "Getting to Know Your Body". It's easy to notice because it is a different color than the actual Tracing Book information. The information which is in this later chapter is not a set of instructions for how to make a Tracing Book, but rather it is meant to be useful information for learning to understand your body better. You can use the information in this section to become better at explaining your symptoms or side effects to your doctor. It is hoped that by understanding how the different parts of your body work, or by just being able to name them, you will become better at managing your health and understanding your treatments.



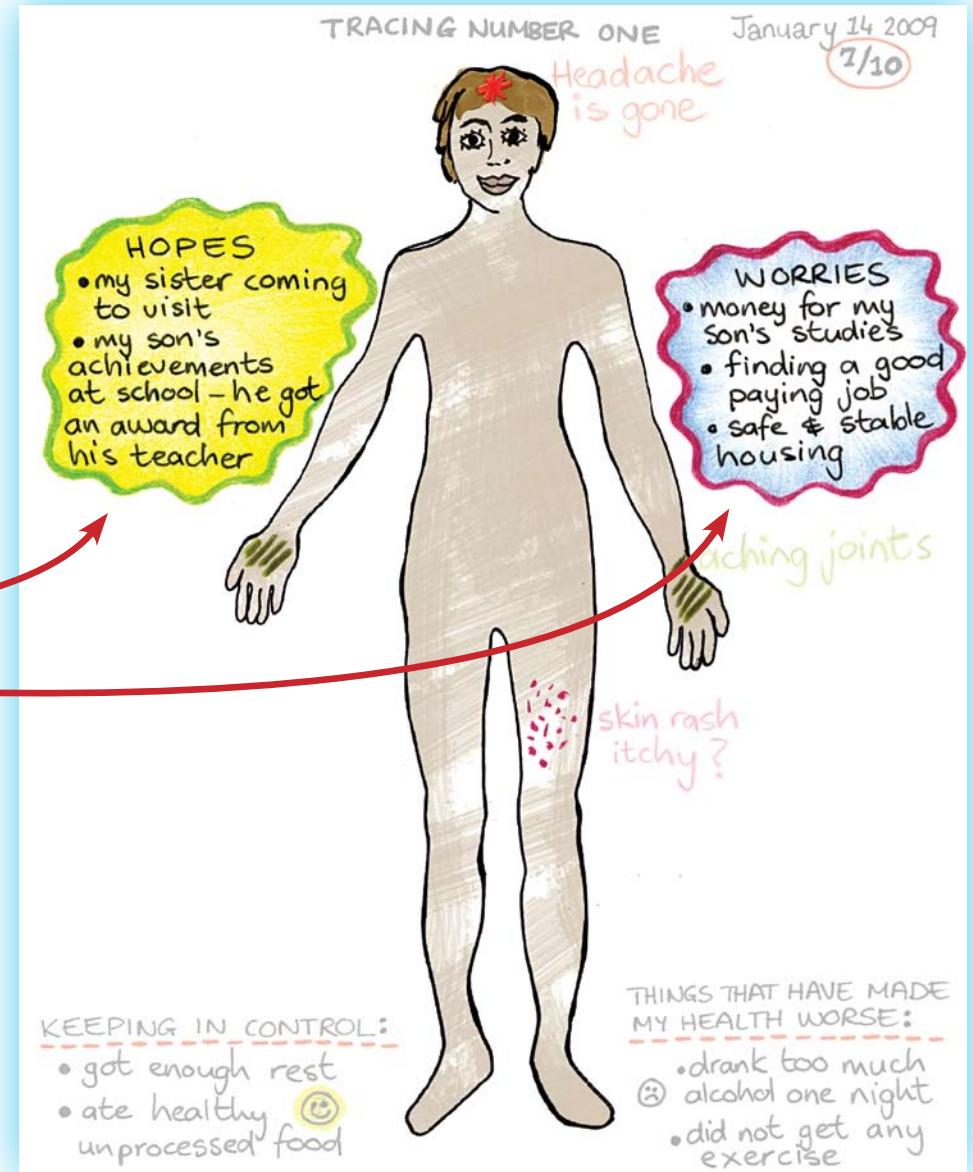
Important happenings in your life this week

The theme we want to introduce next relates to your health right now, at this moment. Remember this is the same body tracing that you began from Page 8 of the manual but we are just adding some extra themes or prompts.

Think of some important happenings in your life this week.

Somewhere on your tracing book use a symbol and a couple of words to represent:

- Things you feel hopeful about right now
- Things that are worrying you at the moment



Adherence

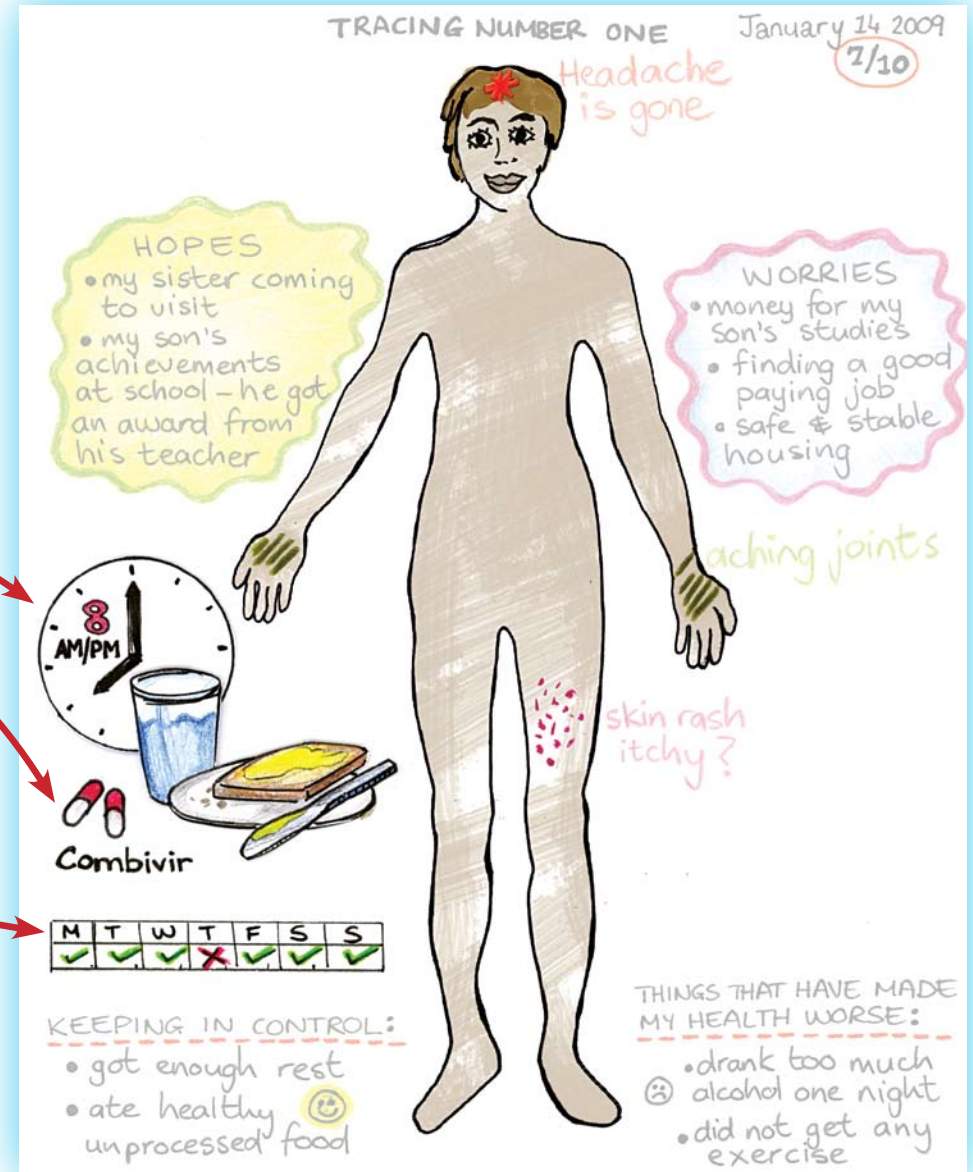
Now adding to the same body tracing we want to add the theme of adherence.

Remembering to take medications properly and on time can be challenging. With HIV, it's very important to keep your virus under control and this requires a lot of focus and energy on your part.

On your tracing use a symbol to represent:

- When you take your HIV medications (ARVS or HAART)
- The type of drug combination that you are taking
- What helps you remember to take your ARVs?
- Have you forgotten any doses this week?

You can see here that Mary used some symbols rather than words to represent answers to these questions.

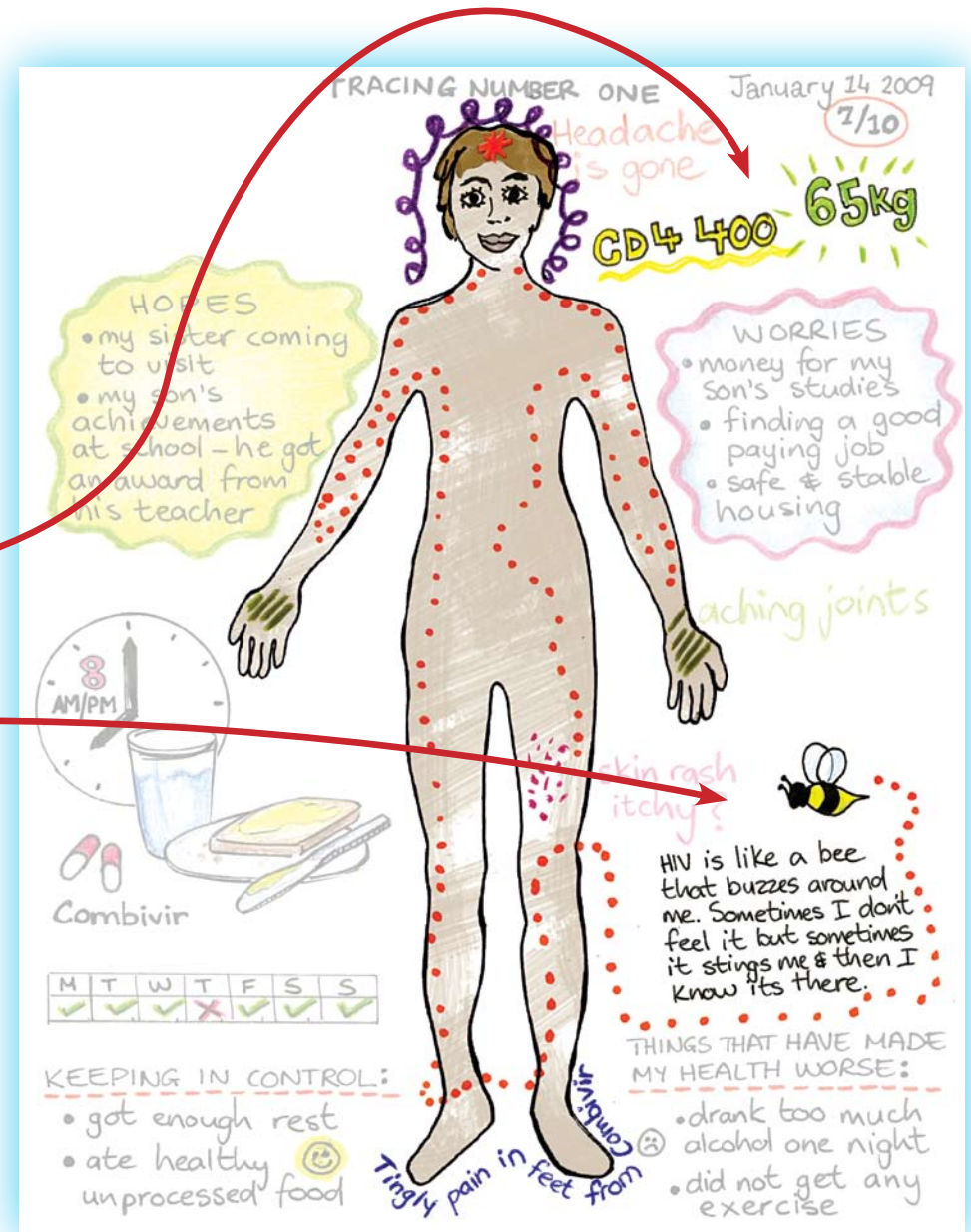


The Virus

Adding to the same body tracing, we now want to add the theme of the virus, known as HIV. HIV is something that lives in your body but most days you might not feel it at all. Think about the virus and where you feel it.

On your tracing make a mark, note or symbol to represent the following:

- How does HIV look to you? Do you have a symbol or image that you use to show how you see or feel the virus in your body?
- Add your CD4+ cell count and viral load to the page if you know them.
- Add your weight if you know it.
- Are there things happening in or on your body that you recognize as side effects of any medication that you are on? Mark and note these.
- Where in your body do you tend to feel HIV most?



Your Body



Let's think about things that can happen in and on your body. These can be things that happen as a result of HIV, the medications you take, or from life itself. Look at the list of symptoms and side effects on page 14.

You will look back at this list many times as you do more tracings over the next few weeks. We don't recommend that you tick things off on this list or you will see it get worn out over time. **Rather** choose the things from this list that you want to show on your **tracing** and add a symbol or a few words to the tracing you have been doing up until this point. Just choose the things from this list that seem important or related to what is happening in your body and mind at this time. As long as you make notes next to what you add to your tracing, you won't forget what it is that you meant.

We have made a copy of this list and attached it at the end of this book. You might wish to make copies of this list for yourself or your friends. Feel free to take the list out of the book and use it in a way most useful for you.

Here is the list for you to consider when adding things to your tracing:

- Are you coughing?
- Do you sweat at night?
- Do you have a fever?
- Are you losing weight?
- Do you have rashes, scars or marks on your skin?
- Are you having stomach problems such as diarrhea, constipation, nausea or vomiting?
- Are you having difficulty breathing, shortness of breath or pains in your chest?
- Are your glands swollen or sore?
- Are you having headaches or pain around your head?
- Do you have sores or bleeding in your mouth?
- Do you have thrush?
- Do you have any new or recurring STDs/STIs?
- Have you noticed loss of body fat on certain parts of the body?
- Have you noticed a gain of body fat on certain parts of the body?
- Do you have any sores or ulcers in or on any parts of your body?
- Have you been experiencing pain, "pins and needles", numbness or tingling, anywhere?
- Are you losing appetite?
- Are you eating more than usual?
- Are you having problems remembering things?
- Are there times when you feel confused or disoriented?
- Are you having difficulty falling asleep?
- Are you having bad dreams or nightmares?

We have just chosen three examples from the list and marked these on the tracing. These are just examples.

TRACING NUMBER ONE January 14 2009 7/10

Bad dreams not sleeping

Headache is gone

CD4 400 65kg

HOPES

- my sister coming to visit
- my son's achievements at school - he got an award from his teacher

WORRIES

- money for my son's studies
- finding a good paying job
- safe & stable housing

aching joints

Strange bumps recurring

skin rash itchy?

HIV is like a bee that buzzes around me. Sometimes I don't feel it but sometimes it stings me & then I know it's there.

THINGS THAT HAVE MADE MY HEALTH WORSE:

- drank too much alcohol one night
- did not get any exercise

KEEPING IN CONTROL:

- got enough rest
- ate healthy unprocessed food

Combivir

Tingly pain in feet from Combivir

8 AM/PM

Combivir

M	T	W	T	F	S	S
✓	✓	✓	✗	✓	✓	✓

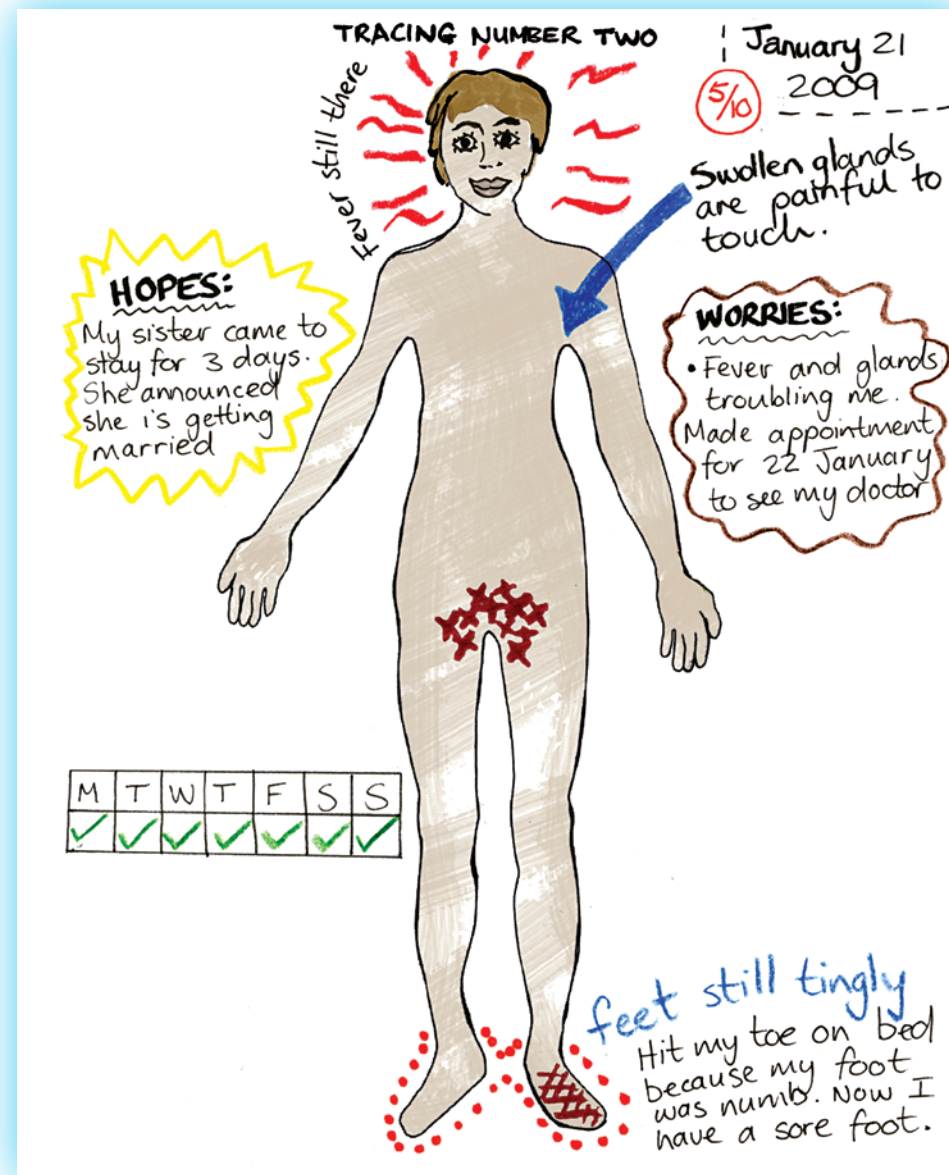
You have now completed the Tracing Book exercises **for your first tracing**. You can continue each day to add to the tracing you have made, or you can make a new tracing each day, every other day, or once per week. It is important that you continue to follow the exercises you have just done so that your health concerns and triumphs can be acknowledged and monitored by you and anyone you choose to share your book with.

There are different ways in which you can track your wellness or illness. For one week, you may continue to add to the tracing which you made on Day 1. You may find yourself adding to that tracing over a couple of days, or you may wish to start a new tracing each time. It all depends on your health and what you want to make notes of at the time.

You may also wish to begin a new tracing each day, every other day, or once weekly. It's up to you. **But do remember to mark the date when you add something new to an existing page or when you begin a whole new tracing.** This is important for many reasons. One reason is that it helps to keep track of things like side effects and other illnesses you may be experiencing. Coughs, rashes, and flus can get better or worse over time and it's important to keep note of dates if you wish to use a Tracing Book to help you and your doctor monitor your health.

Mary... 1 Week Later

On this page we have added another tracing done one week after Mary's first tracing. Take note that on the top right of her page she has written "January 21" (all the previous tracings were done on "January 14"). Next to that she has written **Tracing Number Two**. She has also added how she is feeling as "5 out of 10". This will help you see what she has added to her tracing and what things she has left out according to what she feels is most important for her at the moment.



Side Effects and Getting to Know Your Body



Congratulations, you just finished with the instructions or prompts needed for making your first tracing. This next chapter is designed to help you understand your body and side effects better so that you can add more accurate information to your tracings. You can also use this chapter in conjunction with the third manual in this series. The manual is called “Understanding HIV Basics” and gives you more information on HIV, how it affects the body, and the medications people take to keep HIV under control.

Long Term and Short Term Side Effects

A side effect is something that happens to your body as a result of medications or treatments. Simply speaking, it is an unwanted effect of a drug within your body. Short term side effects are those that will often go away after a few weeks but that may last up to a couple of months.

Some examples of short term side effects of HIV medications are:

- Diarrhea
- Nausea
- Vomiting
- Rashes

Long term side effects are those that often stay with you and don't get better over time. As unfortunate as it sounds, that's what happens as some drugs work to suppress the virus in your body.

Some examples of long term side effects are:

- Lipodystrophy (This is when certain areas of your body lose fat. For example the fat on your bottom may disappear and you may get skinny arms and legs. This happens as a result of certain HIV drugs, most specifically the drugs DDI and D4T).
- Memory Loss or Confusion

Over the next 5 pages, you will become familiar with a new chapter called “Getting to Know Your Body”. The information in this chapter is not a set of instructions for how to make a Tracing Book, but rather it is meant to be useful information for learning to understand your body better. You can use the information you learn in this section to become better at explaining your symptoms or side effects to your doctor. It is hoped that by understanding how the different parts of your body work or by just being able to name them you will become better at managing your health and at understanding your treatments.

Your Body

Your body is like a puzzle. Each organ under our skin fits exactly with the next organ and they all work together to form bodily systems. It is important to recognize where your organs are located in your body. On the following pages you will be able to see where in your body certain key organs are found. This will help you to manage your overall health and any side effects you may be experiencing.

Brain

The brain is part of the Central Nervous System (CNS). The nervous system contains not only the brain, spinal cord, and the peripheral nerves, but it's also the body's master control centre. Your CNS controls your thinking, emotions, consciousness, and awareness. Your peripheral nerves relay information from your senses to your brain. They control bodily processes and regulate behaviour and movement.

Lungs (in the chest)

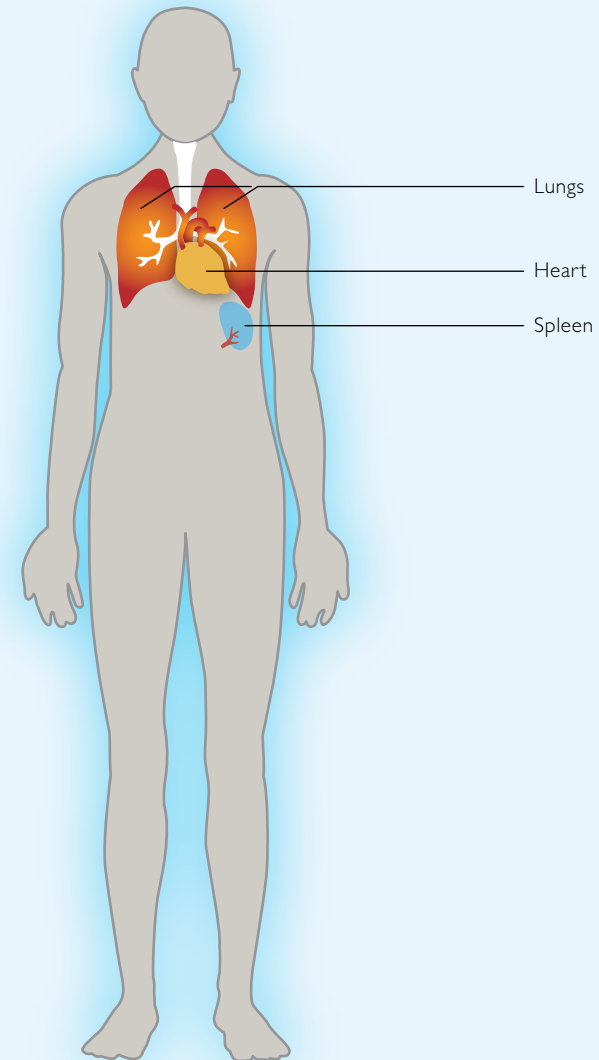
The lungs are part of the respiration and cardiovascular systems. These systems also include the heart, spleen, blood and blood vessels. The lungs bring oxygen into the body and move carbon dioxide out.

Spleen (left hand side just behind where your lower ribs would be)

The spleen destroys old red blood cells and plays a role in the immune system.

Heart (located between where lungs would be and slightly to the left)

The heart pumps blood to the lungs to pick up oxygen. The heart also pumps blood from the lungs to the heart and throughout the body.



Blood

Blood carries oxygen from the lungs by way of the arteries and carbon dioxide to the lungs by way of the veins. Blood carries nutrients, hormones, waste products, and immune cells around your body.

Digestive System

Your mouth, throat, esophagus, stomach, intestines, liver, and gall bladder make up the digestive system.

Esophagus (long tube from the mouth to the stomach that food travels through)

The esophagus is the muscular tube between the mouth and the stomach.

Stomach (sac located under left breast)

Your stomach breaks down food and passes it to the intestines for absorption.

Small and large intestines (located just below the stomach)

The small intestine absorbs food into the body and the large intestine receives undigested food waste from the small intestine. It also reabsorbs excess water and some nutrients. The large intestine helps to eliminate waste from the body. Some people know the large intestine as the colon.

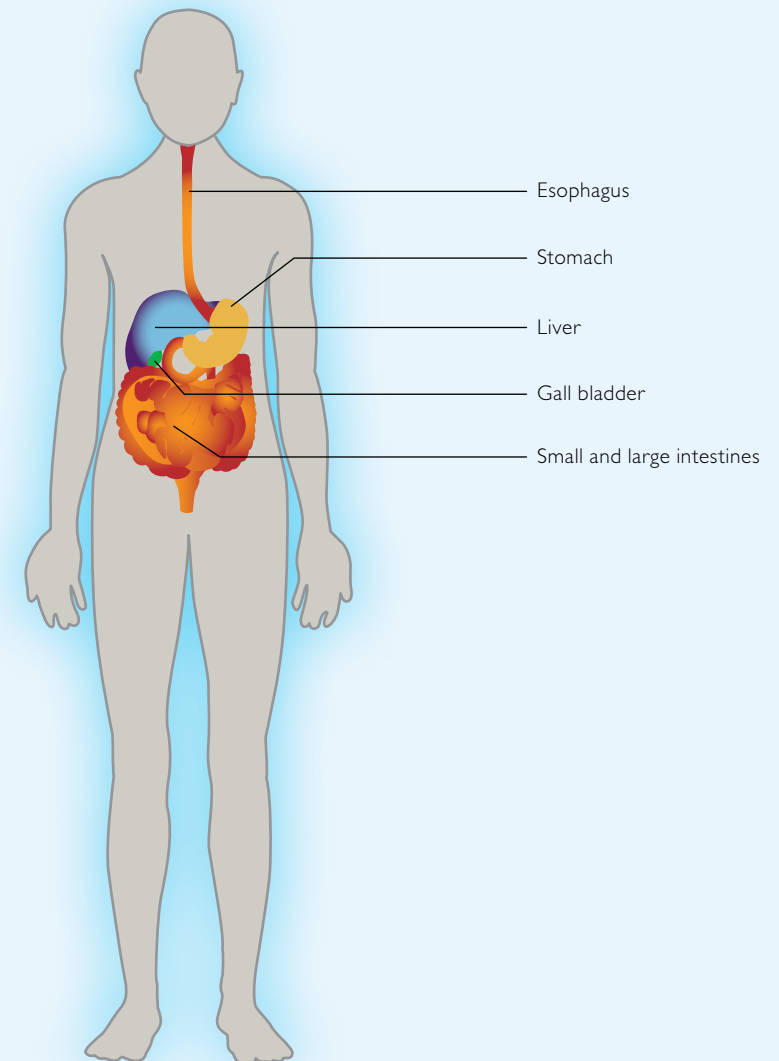
Liver (right side of body just behind lower rib cage)

The liver is the largest organ in the body and helps to:

- regulate metabolism
- store fats, carbohydrates, vitamins, minerals
- absorb proteins
- produce bile for digestion
- detoxify the blood

Gall Bladder

Your gall bladder stores the bile that the liver produces. It's actually connected to your liver.



Kidneys (located in the back of your torso on either side of the spine just below your rib cage. They are about the size of your fist and are, as their name suggests, shaped like kidney beans.) Your kidneys help to clear toxins and balance levels of water and chemicals in the body. Water and waste products are turned into urine by the kidneys and excreted from the body.

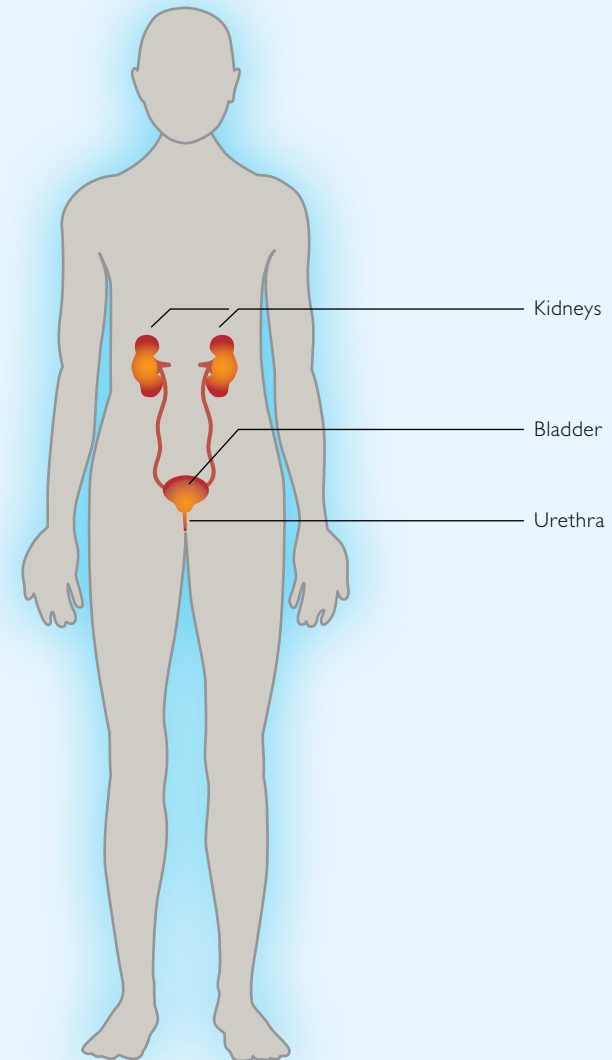
Bladder (located in the pelvis)
Urine is passed from the kidneys into the bladder and held there until it is passed out of the body.

Urethra or Urinary Tract

In a woman this is found just above the vaginal opening.

In men, it is at the tip of the penis.

The urethra and urinary tract eliminate urine from the bladder out of the body.



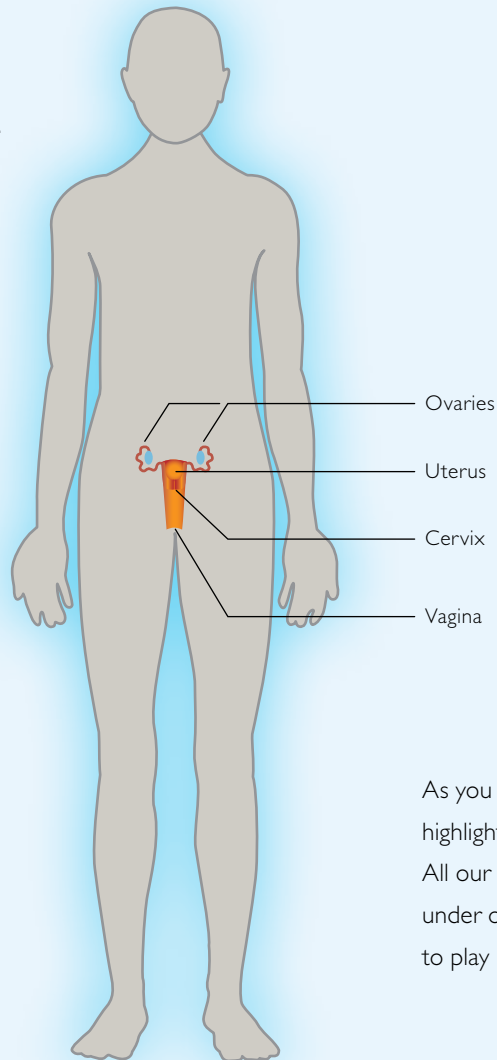
Female Reproductive System

Ovaries - pair of oval organs about 3 cm long found in front of the pelvis. Ovaries produce eggs as well as female sex hormones.

Uterus - hollow, muscular organ in the female pelvis. It receives eggs from the ovaries. A fertilized egg will implant itself in the lining of the uterus where it will develop.

Cervix- lower part of the uterus that opens to the vagina.

Vagina - most exterior part of the female genitals. It extends from the cervix to the outside of the body.

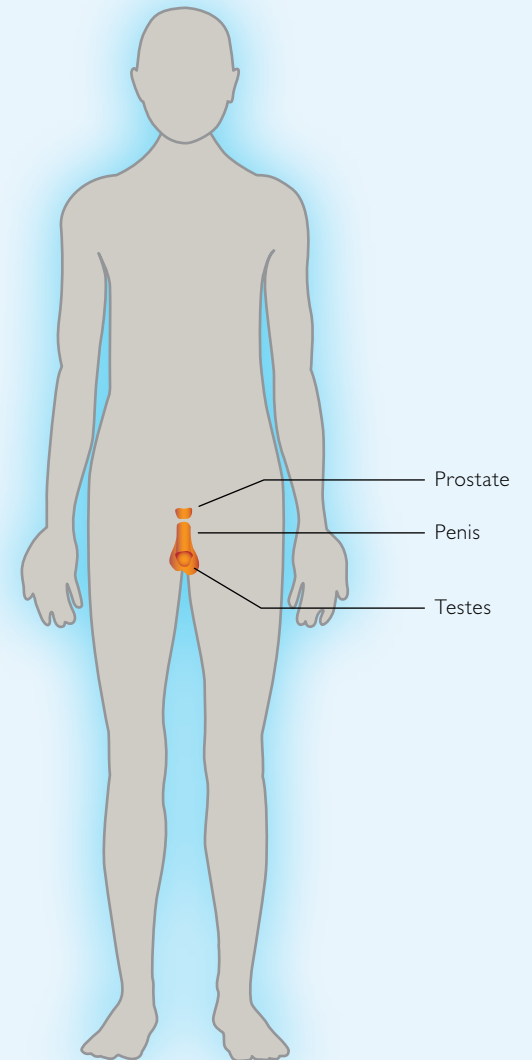


Male reproductive system

Penis - male reproductive and sexual organ. It is also used for urination.

Testes- produce sperm and male sex hormones (testosterone).

Prostate - a walnut sized gland that stores and secrete a component of seminal fluid (the fluid that carries sperm in semen).



As you can see from all the parts of the body we have highlighted, the human anatomy is a complex puzzle. All our parts and systems are very tightly organized under our skin and each part has a very important role to play in our every day life.

Summary

We hope you find this guide book helpful and that you take whatever information that you need for your life at the moment. It is something that we hope will give you the tools you need to make informed decisions about your health and get the support that you need

If you have any questions or concerns about this manual, please write to tsmith@catie.ca or info@catie.ca or knowledge@repssi.org

We also invite you to access the third book in this tool kit. "Understanding HIV Basics" will be available from REPSSI and CATIE in 2009.

Please check both websites for up-to-date information on the release date. www.repssi.org and www.catie.ca

CATIE Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV-related illness and the treatments in question. CATIE in good faith provides information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not guarantee the accuracy or completeness of any information published by CATIE. Users relying on this information do so entirely at their own risk.



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- We hope you will be in touch with any questions, comments, suggestions and stories. REPSSI, PO Box 1669, Randburg, 2125, South Africa, tel +27 11 998 5820, email, knowledge@repssi.org

Simplified List of Symptoms

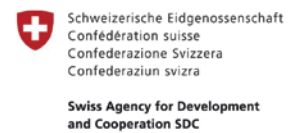


Here is a tear-away list of symptoms particular to HIV and HIV medications (ARVs, HAART) that you can keep close by or make copies of to share with friends and family.

Your Body

Let's think about things that can happen in and on your body. These can be things that happen as a result of HIV, the medications you take, or from life itself. Look at this list of symptoms and side effects. On your tracing make a note or mark relating to the things that are of particular concern to you at this time.

- Are you coughing?
- Do you sweat at night?
- Are you losing weight?
- Do you have rashes, scars or marks on your skin?
- Are you having stomach problems such as diarrhea, constipation, nausea or vomiting?
- Are you having difficulty breathing, shortness of breath or pains in your chest?
- Are your glands swollen or sore?
- Are you having headaches or pain around your head?
- Do you have sores or bleeding in your mouth?
Do you have thrush?
- Do you have any new or recurring STDs/STIs?
- Have you noticed loss of body fat on certain parts of the body?
- Have you noticed a gain of body fat on certain parts of the body?
- Do you have any sores or ulcers in or on any parts of your body?
- Have you been experiencing pain, "pins and needles", numbness, or tingling, anywhere?
- Do you have a fever?
- Are you losing appetite?
- Are you eating more than usual?
- Are you having problems remembering things?
- Are there times when you feel confused or disoriented?
- Are you having difficulty falling asleep?
- Are you having bad dreams or nightmares?



Symph^αsis

