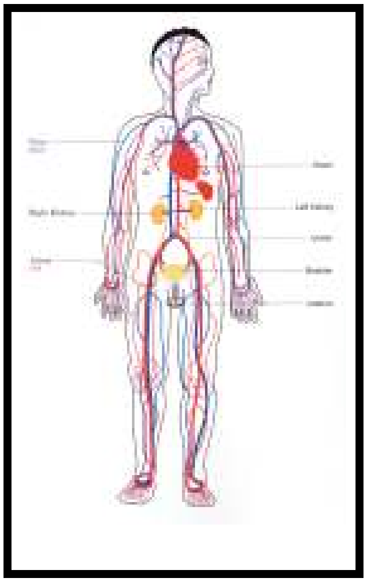
Mapping Workshop Manual



AIDS and Society Research Unit

Centre for Social Science Research

UNIVERSITY OF CAPE TOWN

Disclaimer

The photos that feature in this workshop manual reflect a wide range of people in different contexts and their inclusion does not infer anything about HIV status.

Acknowledgements

This manual is based on previous work done by Jonathan Morgan, Lindsay Rabinowitz, Beatrice Were, Colin Almeleh, Anya Subotsky, Kylie Thomas and Lisa Stratton. The body mapping exercise draws on work done by Jane Solomon. Contributions have been made by Nicoli Nattrass, Lauren Kahn, Jo Stein, Jolene Skordis-Worrall, Margo Russell, Nondumiso Hlwele and the Bambanani Women's Group.

The Mapping Workshop Manual is a working document. It changes according to relevant research, and experiences running workshops in support groups. This version of the manual was rewritten and redesigned by Annabelle Wienand.

http://www.cssr.uct.ac.za/asru.html

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Introduction

The tools described in this manual have been developed by the AIDS and Society Research Unit (ASRU) which is part of the Centre for Social Science Research (CSSR) at the University of Cape Town, South Africa. The manual is a working document which changes as we get feedback from workshop participants and facilitators. The tools and techniques described in this manual are the result of work done primarily by the Bambanani Women's Group (also known as the A-team) who worked closely with ASRU researchers for six years.

The manual offers ideas for workshops and approaches to HIV literacy. Different exercises aim to increase knowledge about HIV and psycho-social support for both people infected with and affected by HIV. The exercises can also be used to train people such as Community Health

Workers, Treatment Literacy educators and others who work in clinics, support groups, youth groups, businesses and schools. It aims to give people skills so that they can share their knowledge of the social, emotional and physical sides to living positively with HIV and AIDS.

Many of the exercises and tools in this manual are based on the ideas of peer education and narrative therapy. Peer education trains people so they are able to share their knowledge with people in their community in either formal situations like support groups or informally when talking to their neighbours. In this way people are able to share their opinions, ask questions, learn from the peer educator and from each other's life experiences.

Peer education has been used to spread information about HIV/AIDS and Highly Active Antiretroviral Therapy (HAART). It has also been used to help people living with HIV to make the kind of decisions that help them to live positively with HIV. Often the environments and communities where people live make it difficult for them to make the best decisions about their health. Peer education aims to make a difference not only for individuals, but also the larger community by spreading knowledge about HIV/AIDS and HAART.

Narrative therapy encourages people to think and talk about their life stories so that they can accept their lives and make positive decisions for the future. Michael White and David Epston pioneered narrative therapy work and it has been used in social work, nursing, psychology and psychiatry. This manual shows people how to make journey maps, memory books, body maps and social maps.

Background

Memory Boxes and Books

This manual describes how to make Memory Books. Memory work was originally used before antiretroviral treatment (HAART) was available in Southern Africa. It aimed to help parents to disclose their status to their children and make plans for the future. The idea was developed in the early 1990's by Carol Lindsay-Smith, Beatrice Were and a group of HIV-positive mothers in Uganda. The mothers decorated and wrote on boxes and placed important documents, like birth certificates, inside them. Others wrote memory books that told stories they wanted their children to remember and included photographs and pictures.

Now that HAART is more widely available and there is more information and education about HIV/AIDS the social and political context of the AIDS pandemic is different. This does not mean that memory books are no longer useful. They are still used by HIV-positive people and those who work with them to think about issues that still affect communities and individuals living with HIV. With antiretroviral treatment people living with HIV have the opportunity to live increasingly productive lives, but challenges like stigma, poverty, unemployment and gender violence still remain. Like many of the other exercises in this manual, memory books encourage people to think critically, develop new understanding and ultimately live informed and positive lives.

Body Maps

Body maps have been used in different parts of the world as either education or art therapy. This manual describes how to trace around the body as a starting point for creating a body map that can be used to explore ways of understanding the body and HIV. The original idea for this technique came from the *Longlife Project* that was run by Jonathan Morgan and Kylie Thomas in 2002 and 2003. Thirteen women met over three months with artist Jane Solomon to create life-size drawings that recorded their journey of living with HIV. The finished works have been exhibited in South Africa and abroad as a set of limited edition fine art prints. A book called *Longlife - Positive HIV Stories* was also published recording the lives of the Bambanani Women's Group.

Visual Body Map

A Visual Body Map is a visual educational tool representing the different systems (i.e. circulation system) in the human body. It has been used to increase people's biomedical understanding of how HIV and AIDS affect the human body. The Visual Body Map was developed by Fiona Mendelson, Lyn Lamofsky and Colin Almeleh. It also has an Educator's Guide with the names of the different parts of the body and information about each system in the body. The Visual Body Map and the guide can be used in schools, support groups, clinics and many other places by educator's, nurses, Community Health Workers, Treatment Literacy Practitioners and peer educators. They can be ordered from the AIDS and Society Research Unit at the University of Cape Town.

Why storytelling?

Many of the exercises in this manual encourage people to think about their lives and social environments. It is important to make the link between sharing life stories and healing and learning. The workshop facilitator can assist in this process by asking questions like:

- Do you think storytelling is important? Why or why not?
- Is storytelling an important part of your culture?
- Did your parents or grandparents tell you stories about their lives?
- Do you feel the need to tell your story? Why or why not?
- Can others learn from your life experiences? How?
- Has anyone's life story changed the way you live? How?
- When you make a record of your own history (memory book, body map or journey map), what do you want to do with it?
- Are you going to show it to other people, your family, friends, or do you want to keep it a secret, like a personal diary?

Learning what you want to Learn

It is very important that the workshop participants are part of the learning process. At the beginning of each workshop or exercise the facilitator should ask the participants what they want or hope to learn from being at the workshop. It is a good idea to make a list and keep it until the end of the workshop so the group can go back and see if they have learnt everything they wanted to. It is encouraging and motivating to start a workshop with a clear idea of what you want to learn. It might be good idea to ask participants the following questions:

- Why did you come to the workshop?
- What do want to learn during the workshop and why?
- Where and how do you hope to share what you have leant?
- What work do you do? Do you think this workshop can help your work?
- What is the most important thing you want to learn about HIV/AIDS?

Memory Books[1]

Making memory books is a popular and important way of discussing HIV in our lives. Memory books can also be used to talk about other illnesses or challenges people face. Working on a memory book includes different exercises. Depending on the workshop group some exercises can be included or left out. For example the journey map (page 15), the social support (page 21) and disclosure maps (page 18) and the sexual and reproductive map (page 22) can be added to a memory book. Memory books are like diaries. They give people the chance to think and discuss their lives and make plans for their futures.

Memory books are very good for support groups, but can be used in many other places to help people to accept their HIV-positive status and make decisions for their future. People can decide what they want to do with their memory books. Some memory books have been kept hidden.

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[1] The memory book and specifically the windows exercise originates from previous work done Jonathan Morgan in *Finding Mr. Madini*, Jonathan Morgan and the Great African Spider Writers, (David Phillip, 1999). Kylie Thomas contributed to the original ideas when she worked at ASRU in 2001. The Memory Book activity as described in this manual is largely based on Morgan's work while director of the Memory Box Project (2001 – 2003).

Others have been made together with family members. Some people have even given their memory books to their community library so that more people can read about their lives with HIV.

Exercise 1: Making a Memory Book

Materials

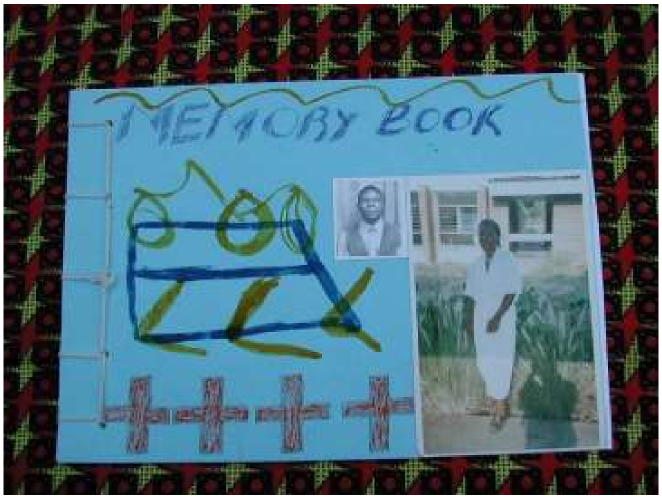
- 2 pieces cardboard per person for the back and front covers (boxes can be collected from supermarkets and cut to A4 size)
- A4 paper for the pages (new or recycled paper printed on one side can be used)
- 1 piece of string or wool per person
- 1 box of paper clips
- long thick nails (at least 5, but more if the group is large)
- hammer or a large stone or brick

It is a good idea if the workshop facilitator makes one memory book as an example before giving the workshop. You can introduce yourself through your memory book. This is a good way of building trust and also sets an example for respecting confidentiality when people share their life stories with the group.

1. Cut two pieces of cardboard to make the covers of the book.
2. Decide how many pages you want and put them in between the covers.
3. Take a nail and hammer it through both covers and all the pages about 2cm from the left hand edge of your memory book. It makes sense to work in pairs and help each other to do this.

4. Leave that nail in place and make about 4 or 5 holes in line with the first hole with a second nail.
5. Take a paper clip and straighten it until it is bent only once in the middle. Take a piece of string about 1 meter long and thread it through the paper clip like a needle.
6. Thread the string through the holes to sew the book closed. Tie a knot in the string.

Exercise 2: Drawing Techniques and Book Cover



Materials

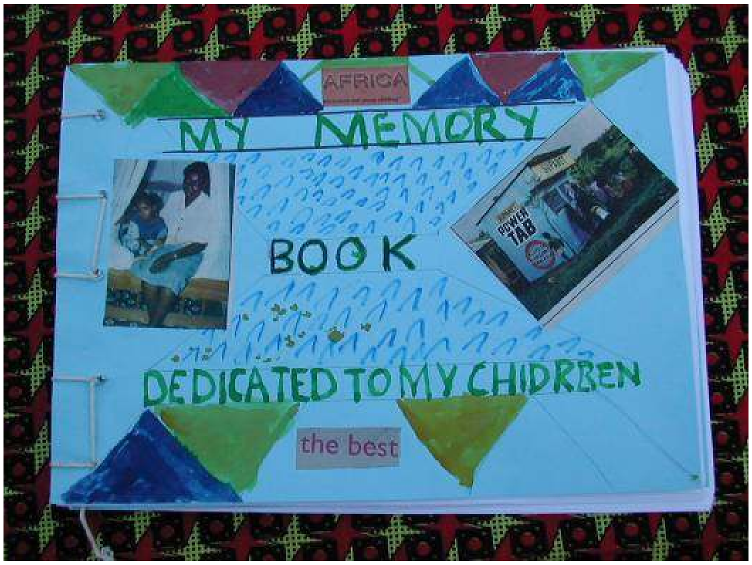
- wax crayons
- liquid food colouring (can be diluted with water to make it go further)
- paintbrushes or ear buds
- *or* to make it simpler pencils and pens can be used but are less creative and fun than crayons and food colouring.

1. Draw or write pressing quite hard with the wax crayon.
2. Paint over your drawing with the food colouring.
3. See how the wax does not allow the food colouring to touch the paper and the great effect this creates. Experiment with different colours. It is usually better to use a light crayon with a dark food colouring and dark crayon with light colouring.

4. Choose a title for your memory book and decorate the cover. Photographs can also be stuck to the cover.

Exercise 3: Dedicating the Memory Book

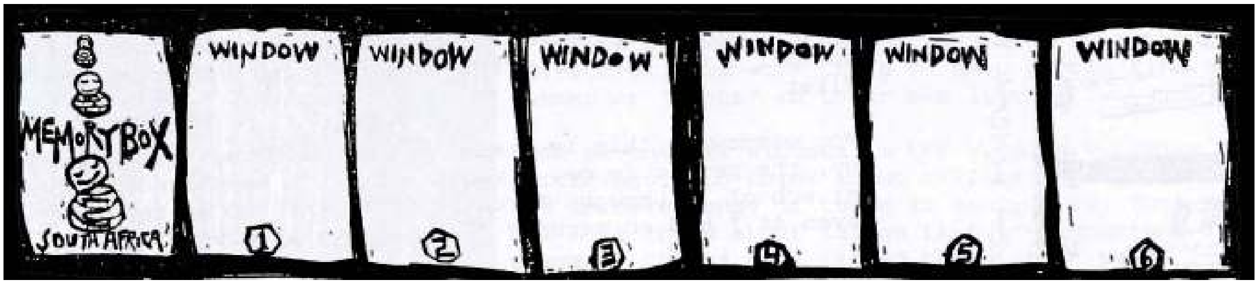
1. Discuss what it means to dedicate something to other people. Has anyone in the group seen or read a dedication before? Some examples of a dedication might be:
    - This book is dedicated to my mother and my father, may they rest in peace.
    - My Memory Book is dedicated to my children. May they be safe and happy forever.
    - This book is dedicated to my life. May I have a positive and happy future.



2. Open the memory book to the first page and write the dedication. You can also decorate this page or stick in photographs of the person or people you have dedicated it to.

Exercise 4: Windows

1. The Windows exercise is about choosing six important stories or parts of your life. The workshop facilitator can photocopy the Windows picture below (or in the Appendix on page 67) for each person in the workshop. Or a page in the memory book can be divided into six blocks or windows.



2. Which stories or parts of your life are important for you? Each window is a story about you or a part of your life. Maybe you want to begin with where you are in your life now. Or maybe you want to remember something that happened in your past. Write a sentence or draw a small picture in each of the six windows.

Busi explained her windows as follows:

PLOT/ THE FIGHTING SPIRIT EVEN WHEN THINGS ARE MORE TOUGH.

- For window 1, I drew when I was 5 years old, as you can see the person looks sad, it was when my troubles started.
- For window 2, I drew a book, it symbolises when I started school, I was so excited, the family who adopted me bought me a uniform and the mother of the house accompanied me to school, I was good at school and in Standard 5 I started to come first.
- For window 3, this is a step ladder with the arrows going up, the person is me, I was starting to have a good progress at school, I thought I would get to the top of the ladder, even if I had no parents I would have an education.
- For window 4, the arrows are going down, I draw myself the day I had to leave school, the family were not treating me well, like a slave in fact, I went to Gauteng to someone I thought would be kind to me but she was not, but I really wanted to go to school, so I explained my condition to a principal and a teacher offered to pay my fees for standard 7 and 8, for standard 9 she couldn't so I went to Cape Town and worked in a restaurant, and in '94 I went back to school paying my own fees.
- For window 5, I have drawn a shadow, I got diagnosed and when I heard that me and my child were positive I just sat down and said maybe I should just give up and wait for my dying day, I was confused I was studying for a better life then this HIV thing came in.
- For window 6, when I joined TAC, my life changed, I became a hopeful person, that's why my arms are like that, the confusion and the shadow went away.

Exercise 5: Zooming a Window

This exercise gives people the opportunity to tell the whole story shown in one of the windows. Zooming a window makes the picture or sentence in the window into a longer story. This exercise is important because it gives people a chance to think about their life experiences in more depth. The story from just one window might grow to be many pages long.

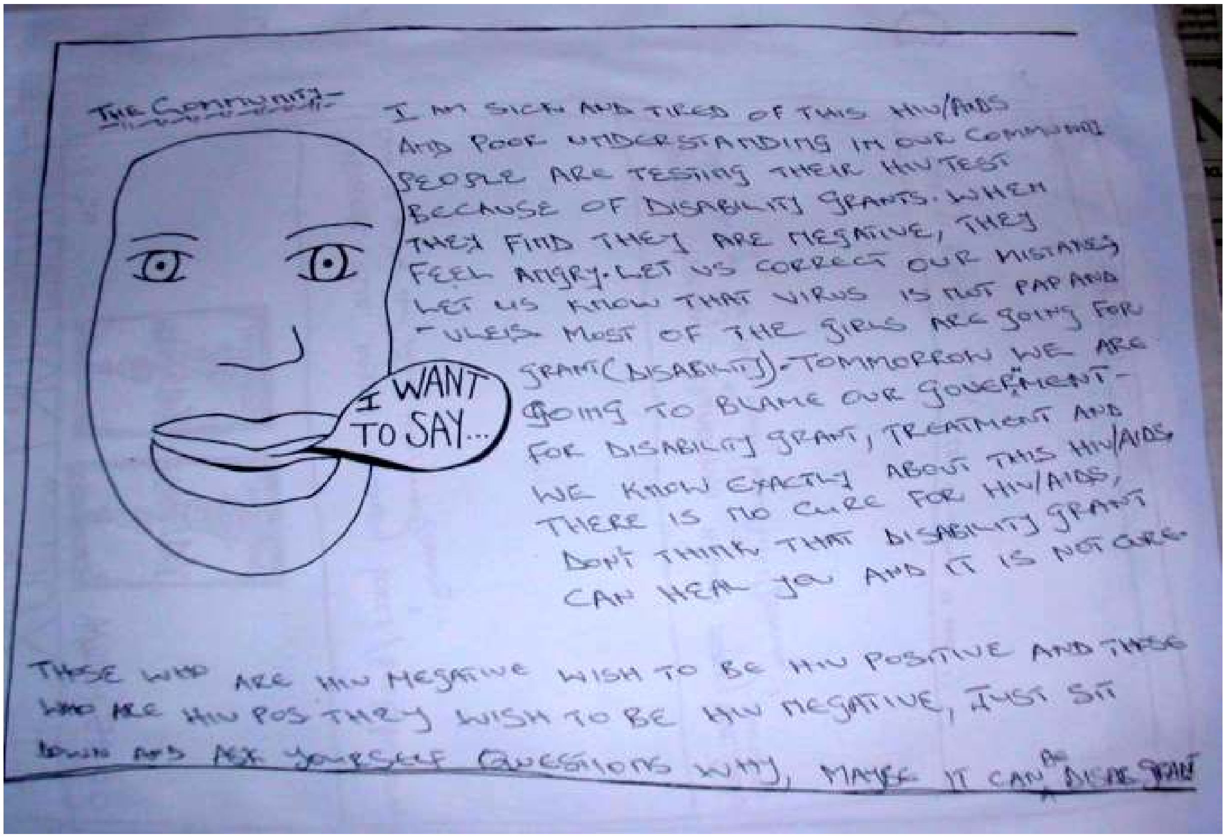
1. In pairs people can explain each of the Windows to their partner.

2. After each person has had a chance to tell their story, they can choose one window to zoom in on. On a new page they can write and describe what is happening in the window they have chosen.
3. If people want to they can zoom all the windows in their memory books. They can do this at home or in a support group after the workshop is finished.

Exercise 6: I want to say…

This exercise allows people to say what is important to them. They can look at their life stories told in their memory books and decide on one important thing they want to write about. Photocopy the picture on page 68 and give one to each person.

Somebody in Pretoria wrote the following in response to this prompt:



THE COMMUNITY-

I AM SICK AND TIRED OF THIS HIV/AIDS
AND POOR UNDERSTANDING IN OUR COMMUNITY
PEOPLE ARE TESTING THEIR HIV TEST
BECAUSE OF DISABILITY GRANTS. WHEN
THEY FIND THEY ARE NEGATIVE, THEY
FEEL ANGRY. LET US CORRECT OUR MISTAKES
LET US KNOW THAT VIRUS IS NOT PAP AND
-ULEIS. MOST OF THE GIRLS ARE GOING FOR
GRANT(DISABILITY). TOMMORROW WE ARE
GOING TO BLAME OUR GOVERNMENT-
FOR DISABILITY GRANT, TREATMENT AND
WE KNOW EXACTLY ABOUT THIS HIV/AIDS.
THERE IS NO CURE FOR HIV/AIDS,
DON'T THINK THAT DISABILITY GRANT
CAN HEAL YOU AND IT IS NOT CURE.

THOSE WHO ARE HIV NEGATIVE WISH TO BE HIV POSITIVE AND THOSE
WHO ARE HIV POS THEY WISH TO BE HIV NEGATIVE, JUST SIT
DOWN AND ASK YOURSELF QUESTIONS WHY, MAYBE IT CAN BE DISAB GRANT

Depending on the group and the time available other exercises such as the journey map, social support map, disclosure map and sexual map can be added to the Memory Book. People can use their Memory Books as diaries and continue to write in them after the workshop is finished.

Journey Mapping[2]

The journey map encourages people to think about their life stories and draw and write about important events or times in their lives. Each participant draws their own journey map that shows their life from the day they were born to where they are now. It aims to encourage people to think about how their journey through the communities where they have lived has shaped where they are now. In this manual the focus is on talking about HIV, but journey maps can be used in a number of other ways to talk about other illnesses and challenges that people face in their lives and in their communities.

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[2] This work draws from an original idea piloted by Jonathan Morgan and Jane Solomon with the !Xhun San people in Schmidsdrift, Kimberley, South Africa. It has subsequently been rewritten by Colin Almeleh, Anya Subotsky and Nondumiso Hlwele.

Materials

- Coloured pens, pencils, wax crayons
- Larger pieces of paper are recommended. A3 photocopy paper or newsprint can be used.

Instructions

1. Explain the idea of drawing a map showing where you have been, what you have done and what has happened in your life. Encourage participants to look at the different stages in their lives and ask them:
    - What did you do in these places?
    - How old were you?
    - What about this place or this time in your life has made you remember it?
2. Write the name of the place where you were born. Write the date next to a picture of the place or something you remember about it.
3. Mark and write and/or draw the different places you have lived and where you have moved. Put a date to each place. Write why you moved to these places.
4. Where did you go to school? What kind of education have you received? Mark this on the journey map.
5. Where have you worked? Where have you looked for jobs? When did this take place? Mark this on your journey map.
6. What other travels or movement have you made? Have you been for a holiday somewhere? Did you do travelling for your work? Do you visit family or relatives somewhere? Mark this on the journey map.
7. Think about the different stages of your life. Which stages were happy and which were times of struggle and difficulty?

8. Think of symbols to represent each phase. For example, a tree might represent a time in which you felt strong and full of growth. A storm cloud might symbolise a time of struggle, and a medicine bottle might speak of illness or wellness.
9. When on your journey map did HIV come into your life? How did you find out? Try remembering the first thing that came into your mind when you found out your HIV status. Mark this place with the date and a description of what happened.
10. When you look at your journey map, how has HIV affected your life? What things have you changed in your life because of HIV? What have you done to live positively with HIV? Think about how you feel at the moment. Look at the journey you have made to get to where you are today. Draw a picture representing how you feel about your life today.
11. You have made a long journey through many places and through times of struggle, triumph, happiness and sadness. Thinking about where you have come from and where you are now, draw a picture representing your future.
12. What has been the most painful experience of your life? What steps did you take to overcome the painful experience? Mark this in the right place and right time. Try drawing a picture where you describe this experience.
13. When you think about your life and look at it represented here, what stands out as the most shining moment or highlight for you? Mark this in the right place and right time. Draw a picture that represents this positive and happy time in your life.
14. Once you have finished all the instructions, add anything you want onto your journey map.

15. Encourage workshop participants to get into groups of 3-5 people. Everyone can have 10-15 minutes to share their journey maps. Remember to encourage listening, support, confidentiality and caring so that everyone feels comfortable to share their stories. If someone chooses not to share their story that is also fine.

Disclosure Maps[3]

The following activity can be part of creating a memory book or can be done alone as a separate exercise. It encourages people to talk and think about disclosure of HIV-positive status. Disclosure is often very difficult because of the family and social environment that people live in. These exercises look at private disclosure between family members and friends as a way of getting support from these people.

When people begin HAART, they are often encouraged to disclose their status to someone in their home so that person can help remind them to take their medication correctly. Other times it might be good to have someone to talk to about how you are feeling so they can give you emotional support. People can never predict how others will respond to HIV disclosure and they should accept their status and be prepared before they tell someone.

The disclosure and social mapping activity aims to encourage people to make their own informed and thought-out decisions on whether to disclose or not. The exercises encourage people to think of different kinds of support such as emotional, financial, psychological, material,

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[3] The disclosure and social map was conceived by Colin Almeleh, Nicoli Nattrass, Lauren Kahn, Nondumiso Hlwele and Margo Russell, with contributions from participants at a workshop for Voluntary Services Overseas.

social and health-related support. The activity also allows people to discuss possible times they have experienced stigma or fears and concerns they might have about disclosing their status.

It is important not to focus only the negative experiences of disclosure because in many cases people have received wonderful support that has made it so much easier to live positively with HIV. For example, people can get help with their treatment, looking after their children and sexual partners can know that they need to use condoms. There are many benefits and risks when disclosing one's HIV status and it is important that the workshop participants learn from each other's different experiences and make their own decisions.

Materials

- Coloured pens, pencils, wax crayons
- Pieces of paper. To cut costs the back side of used photocopies or a roll of newsprint cut into smaller pieces can be used.

Instructions

1. Draw four concentric circles on a piece of paper.
2. Write your name in the inner-most, smallest circle.
3. Write the date you found out you are HIV-positive next to your name.
4. On another piece of paper make a list of all the people that are important in your life. Next to each name rank each person on a scale of 1 – 3 with 1 very important, 2 important, 3 not so important.
5. Using this list fill in these names in the circles with the very important people in the circle closest to your name, the important people in the

next circle and the not so important people in the outer or biggest circle.

6. Write a brief description of each person next to their name (i.e. nurse, husband, girlfriend, mother, sister, neighbour, cousin, work colleague)
7. Write where these people live (i.e. in your household, near where you live in the same city, or further away in the Eastern Cape etc.).
8. Choose a colour and draw circles around the people you have disclosed to.
9. Fill in the dates and place when you disclosed to the different people.
10. In a different colour draw circles around the people you would still like to disclose to.
11. Everyone can get into groups of three to share their disclosure and social maps if they would like to. Encourage support and confidentiality.
12. In groups everyone can discuss the following questions:
    - Who have they put as the most important people or places in their lives?
    - Have they disclosed to the most important people or the least important people? Why have they disclosed to these people?
    - Who on the chart have they not disclosed to? Why?
    - Who do they want to disclose to in the future? Why?
    - What kind of support do they feel they will receive if they disclose?
    - What kind of environment would they feel comfortable to disclose in?

Social Support Maps[4]

The social support map looks at social support more generally and does not focus on disclosure of HIV-positive status. It can be used after the disclosure mapping exercise or be done as part of a memory book or a body map. The social support map can be done by any group of people and does not focus on HIV.

Materials

- Coloured pens, pencils, wax crayons
- Pieces of paper or drawn directly on a body map. To cut costs the back side of used photocopies or a roll of newsprint cut into smaller pieces can be used.

Instructions

1. Draw around your left hand on a piece of paper.
2. In pairs discuss the different kinds of support that people give such as emotional, spiritual, financial, material etc.
3. In groups discuss all the people in your life who support you. They might help you look after your children, lend you money when you need it, care for you when you are ill etc.
4. Write the names of the most important people who support you in each finger of your traced hand. Write the names of other people who support you in the palm of your hand.

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[4] This exercise was conceived and developed by Colin Almeleh, Nicoli Nattrass, Lauren Kahn, Nondumiso Hlwele, Margo Russell and Annabelle Wienand.

5. Now trace your right hand or ask a partner to help draw around your hand.
6. Think of all the people you give support to in your life.
7. Write the names of all the people you support in the fingers and palm of your right hand.
8. In groups discuss your social support maps. The following questions might help:
    - Who gives you support?
    - What kinds of support do they give you?
    - Who do you support in your life? And how?
    - Do you think you give more support than you receive? How does this make you feel? How can you perhaps change this for the better?
    - Do you enjoy helping people? Why? Why not?
    - Is it easy or difficult for you to receive help? Why?
    - Do you help people who support you? Can you see that giving and receiving support is like two hands working together?

Sexual and Reproductive Map[5]

Everyone knows that we cannot and do not live alone. We are part of families, communities and the country we live in. Our families, our work, our friends and where we live all influence our lives and the decisions we make. Our sexual relationships are one of the most complex relationships and influence many important parts of our lives. Our sexual partners can often give us support and empower us. Or they can disempower us personally with psychological, emotional and physical abuse. Sexual relations can often be part of our social and economic

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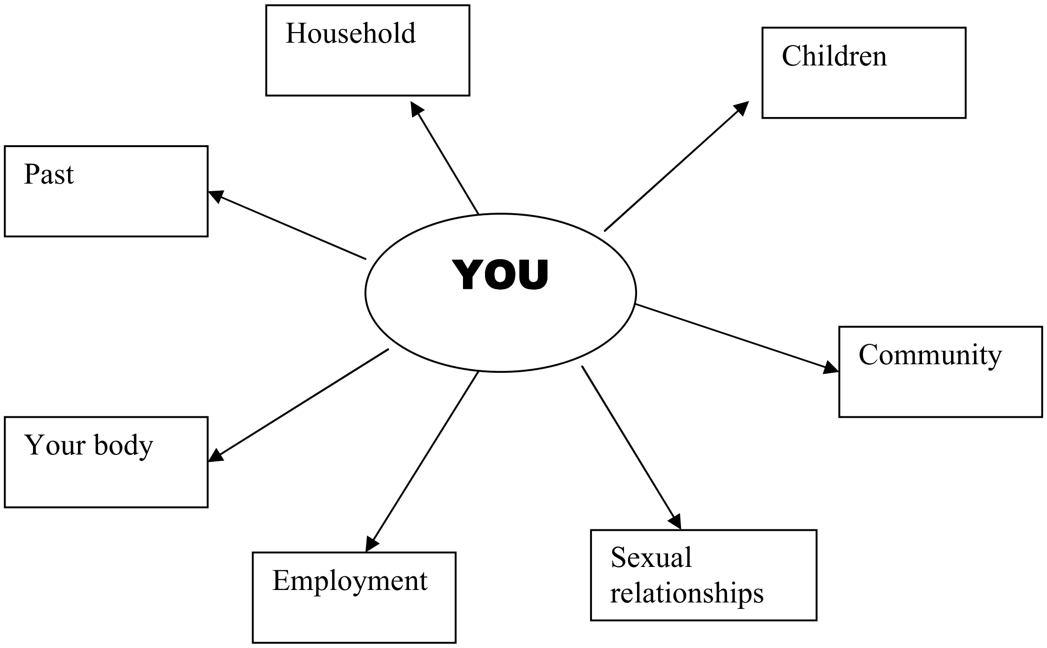
[5] Written by Lauren Kahn and Colin Almeleh with valuable input from the Bambanani Women's Group.

decisions. The following exercises can be done as part of making a memory book or they can be done alone.



Materials

- Coloured pens, pencils, wax crayons
- Pieces of paper or drawn directly on a body map. To cut costs the back side of used photocopies or a roll of newsprint cut into smaller pieces can be used.

Instructions

1. Start the discussion by drawing a 'spider diagram' like the one on page 15 that shows all the different aspects of your life.
2. In pairs or small groups discuss each part of your life and how it affects your relationships, including your sexual relationships.
3. As a large group discuss power and who is able to make the decisions in each relationship. For example, in a work relationship the

employer often has more power than the person who is employed. In families, the decisions are often made by the same person or group of people. In sexual relationships sometimes we share power equally, but sometimes we have more or less power than our partner. You can discuss this generally or from your own experience by answering the following questions about each part of your life:

  - Who has power to make important decisions and choices and to take important actions? Who does not?
  - How does this affect each person? Think of both the negative and positive ways this influences your relationships.

4. In pairs or small groups discuss power between a man and a woman. Think of the roles and responsibilities that are expected of men and women in your community. You do not have to talk about your own personal experiences, but look at what you see around you everyday.
5. Look at the diagram on the next page (if possible give everyone a photocopy of it) and in groups discuss the questions in the blocks.
6. Depending on the group, HIV can be brought into the discussion by asking the following questions:
   - Do people come to be infected with HIV because of unequal power in our sexual relationships? Why? How?
   - Does being HIV-positive change a relationship? How? Why?
   - Many people say that they are scared to get into sexual relationships because they have HIV. How do you feel about this?
7. In a large group discuss ways relationships between men and women can be made better. Remember that different cultures have different expectations of how men and women should behave.

REPRODUCTIVE LIFE

- Child-bearing and bringing up the child or children
- Do you have a choice in this relationship over whether or not to have children and/or how many?
- Do you and your partner share the role of child-rearing and child-support?

PHYSICAL LIFE

- Does your partner respect you and your body?
- Do you have power and choice within you sexual relationship?
- Are you happy with the way things are in your relationship?
- If you or any one you know is abused, do you know where to go for help?

YOU AND YOUR PARTNER

EMOTIONAL and SOCIAL LIFE

- Does your partner give you emotional and social support? How?
- Do you in return support your partner emotionally and socially? How?
- Do you expect emotional support in a sexual relationship? Why or why not?
- Do you talk to your partner about these things?

PRODUCTIVE or FINANCIAL LIFE

- Does your partner support you financially?
- Do you support your partner financially? How?
- How do you and your partner support each other, either with money or food, or helping with your work?
- Do you think there are any problems in your relationship because of money? How could you change this?

Body Mapping[6]

This body mapping exercise aims to assist people to think about, discuss and understand how their life story and HIV have affected their body. The body records our life stories through injuries, scars, birthmarks, illnesses, operations etc. Through a creative and visual process, the body mapping exercise aims to let people see how their body is affected by their lives. Body maps do not have to focus on HIV, but can be used to talk about any illness. Body maps have also been used by different groups of people including victims of political violence and school students.

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[6] The basic body mapping activity was originally run by artist Jane Solomon with the Bambanani Women's Group for the *Longlife Project* in association with Medécins Sans Frontières. This resulted in a book by Jonathan Morgan and the Bambanani Women's Group called *Longlife: Positive HIV Stories* (Double Storey, 2003). Since then it has evolved into its current form through learning from our workshop experiences in many different support groups. The version in this manual draws on experiences from Colin Almeleh, Anya Subotsky, Jonathan Morgan, Nondumiso Hlwele and the Bambanani Women's Group.

Materials

Depending on the budget for the workshop the materials can be chosen accordingly. Pattern card or newsprint are the cheapest options for making the body maps. Pens, crayons, chalk and powder paint can all be used. Materials can be bought at regular supermarkets and stationery shops.

- one piece of large card or paper for each person
- Coloured pens
- Wax crayons
- Powder paint
- sponges and/or brushes
- Basin of water and towel to wash hands and feet after stamping exercise
- Old newspapers to protect the floor of the work space
- Rubbish bags are useful for cleaning up afterwards
- A Visual Body Map or book with drawings of human anatomy

Instructions

1. Choose a partner.
2. Draw carefully around your partner's body with a coloured pen on a big piece of cardboard.
3. When you are finished drawing your partner ask your partner to draw around your body on the same piece of cardboard in a different colour. The two body shapes should overlap each other with one looking like a shadow.
4. Repeat the exercise on another piece of cardboard so your partner has his/her own body map to work on with you as the shadow.
5. Write your name and where and when you were born on the cardboard. Write this nice and big in a place outside of your outline.

6. Choose a colour to represent you and paint around the outline of your body.
7. Choose another colour and colour in the outline of your partner everywhere they are outside the outline of your body.
8. Discuss what your partner’s shadow might mean to you. The following questions might help:
    - Has there ever been somebody in your life who has given you support through happy and sad times?
    - Which of you ancestors might this shadow be? Write their name somewhere next to the shadow and write something about this person and how they influence your life.
9. Paint your hands and feet using a sponge or paint brush and stamp them on your body map where your hands and feet are. Wash your hands and feet in the basin of water.
10. When you are feeling down or depressed, where in your body do you feel your emotional pain? Mark these places.
11. What part of your body gives you strength to overcome times of struggle? Feel where your place of personal power in your body is. Mark this place.
12. Choose a symbol to represent you. The symbol should represent your strengths and weaknesses. It could be a plant, an animal or an object. It can be anything that has meaning for you. It could also be a combination of a few symbols. Paint or draw the symbol onto your body map where you marked your place of personal power.
    - Some people have drawn Table Mountain representing their ties to Southern Africa.
    - Others have drawn a fruit or vegetable. and
    - Some have drawn farm animals symbolising how their strength lies in the Eastern Cape.

13. Everyone in the workshop can now share their symbols of personal power. The following questions might help to get people talking.
    - What have you drawn?
    - Why did you choose that particular symbol?
    - How does that symbol represent who you are?
    - Share a story from some time in your life which explain the symbol you have chosen.
14. Draw a five-minute self-portrait on your body map.
15. Close your eyes for one minute and try remembering your first memory. Somewhere on your body map paint/draw a picture of your first memory and describe it in a few words next to the picture.
16. Now close your eyes and imagine your future. Draw/paint this future somewhere on the body map.
17. You must now think about your physical body and your skin. Your body records all the marks that represent stories that have happened in your life. Notice all marks, birthmarks, beauty marks, scars, stretch marks, moles, pimples, rashes and wrinkles and laughter lines on your body. Draw these marks onto your body in the correct places. Next to the mark write something about how it came to be there.
18. Feel where else in your body, underneath the skin you feel strong emotion, joy or pain. Maybe you have had an operation or some of your organs have been damaged for some reason. Mark these places using colours and patterns.
19. Have you had TB in your lungs? Do you have heart or liver problems? Which of the organs in your body tell a story? Find an anatomical drawing to use for reference if you don’t know what the organ looks like. Write next to your body outline what happened there and when.

20. You can also show emotion on your body maps. Draw places on your body where you feel different emotions and write a sentence explaining each one.
21. We all get sick, but some illnesses are worse than others. Some things in our lives make it easier or more difficult for us to get sick. In pairs or small groups discuss this and if you like you can write it on your body maps.
22. Talk about your last illness experience in small groups or pairs. (This exercise is optional depending on the group). The following questions might help:

- How long ago was this?
- How did you know you were ill?
- Did you tell anyone that you were not feeling well? How did they react?
- Where you able to carry on with your normal responsibilities while you were sick?
- How did you know what to do?
- Did you take any medicine? Where did it come from?
- Did you have to pay any money to get well? Where did this money come from?
- Do you think you should have done anything differently?

23. Some sicknesses are very common and others are not. Think about yourself, your family and your community. This exercise encourages discussion about HIV/AIDS together with other illnesses. In a large group discuss the following questions:

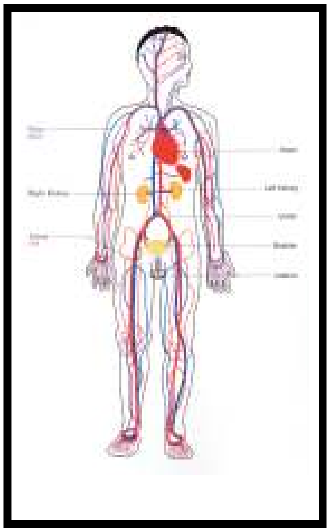
- Which illnesses would you say are very common?
- Which illnesses would you say are very rare?
- Which illnesses do you and your family fear <u>most</u>? Why?
- Which illness do you and your family fear <u>least</u>? Why?
- Would any of these illnesses prevent people from speaking to you or treating you normally? Which? Why? How?

24. Ask yourself how HIV has affected your body? Has HIV left scars? What has happened to your skin? What opportunistic infections have you experienced and what did you do to heal yourself? The following list might help this exercise.

Stage 2	**Stage 3**	**Stage 4**
Weight loss	Chronic diarrhoea	Severe disease
Coughs	Lasting fevers	AIDS
Flu	Thrush	Meningitis
Colds	TB (tuberculosis)	Pneumonia
		Kaposi’s Sarcoma

25. This is your body map so feel free to add any other details, colours or patterns that have special meaning to you. Think of a slogan for your body maps that means something special to you. Some examples from past workshops are:
    - Be wise. Condomise.
    - Love yourself. Love Life.
    - One way. One heart.
    - Knowledge protects.
26. Prepare a 5-10 minute presentation of your body map. How do you feel about your body map? What stories does it tell? What have you learnt about yourself and your health?

Visual Body Map Drawing Workshop[7]



This workshop aims to increase knowledge of human biology and how HIV/AIDS affects the body. It works hand-in-hand with the Visual Body Map[8] and is a train-the-train style workshop. This workshop is for people who work in HIV/AIDS literacy and training, including Community Health Workers, support group counsellors and others providing support and education for HIV-positive people. It can be done as a refresher course for people already with experience, or as training for those new to the field. It can also be used in support groups, clinics, youth groups and other environments. The workshop has been informed by previous

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[7] This workshop was written and developed by Annabelle Wienand, but could not have reached this phase without past valuable work done by people and projects affiliated with the AIDS and Society Research Unit (ASRU). Advice and suggestions from Colin Almeleh, Nicoli Nattrass, Nondumiso Hlwele, Salma Ismails, Victoria Ndyaluvana, Thobani Ncapai, Babalwa Cekiso and workshop participants from TAC and HOPE have been essential in shaping the workshop. All illustrations were created by Colin Almeleh and Ohad Shachar.

[8] The Visual Body Map and Educator's Guide were developed by Colin Almeleh and Fiona Mendelson.

training booklets developed for the AIDS and Society's Research Unit's outreach work.

Workshop Aims

The workshop aims to increase biomedical knowledge about HIV/AIDS by using a Visual Body Map (chart of the anatomy of the human body) together with exercises using drawing, group discussion and role play. It also covers issues such as social support for people living with HIV, access and adherence to antiretroviral therapy (HAART) and other practical advice.

How long does it take?

The workshop takes roughly 9 hours depending on the group involved and can be shortened by skipping some exercises. The workshop is broken into sessions that can be used in support groups or other places like youth groups and schools. The workshop is a flexible education tool and people are encouraged to adapt it and use it in whatever way suits them and the work they do. Many of the workshop activities can be done as independent or 'stand alone' exercises with individuals or groups.

What materials are needed?

The materials needed to run a body map workshop can be simple and inexpensive to buy. The basic materials include sheets of paper or card large enough for someone to lie down on and have their body traced. A roll of bulk paper, sheets of brown pattern card or flattened card board boxes are the cheapest options. Drawing materials can include pens, pencils, wax crayons, chalk, charcoal and poster paint or food colouring.

A Visual Body Map is an important tool and used throughout the workshop. Alternatively most public libraries have books on the anatomy of the human body. Visual Body Maps can be obtained through the AIDS and Society Research Unit at the Centre for Social Science Research:
University of Cape Town
Private Bag
Rondebosch 7701
Tel: (021) 650 4656.
Email: kforbes@cssr.uct.ac.za

List of Workshop Materials:
Name tags and pen
Black / white board or large pieces of paper and pen
One piece of card or paper per group
(big enough to lie down on and trace a person’s body)
Pile of pictures from magazines and newspapers
Advertisements for food and household products
Pencils, pens and colour markers
(or wax crayons and food colouring with paint brushes)
Newspapers
Scrap/recycled paper (printed on one side)
Photocopies of a road map of the area
Candle and matches
Scissors (one pair per group of four)
Glue (one pair per group of four)
Zip and lock and key
Balloons (five per group of four)

Session 1

Getting to know everyone (10 min)

As each person arrives, they write a name tag and take a seat in a large circle. Everyone introduces themselves in an active way. Some ideas are:

a) Singing or rhythmic clapping in a circle

b) Each person chooses a picture from a pile cut from magazines or newspapers and uses it to introduce him or herself by talking about the picture and why they like it.

c) Participants are given a few minutes to find a partner to 'interview' so that they can introduce their partner to the group afterwards.

Ground Rules (5 min)

Quickly write up a list asking the group for guidelines or 'rules' they want during the workshop. Ideas might include:

- ✓ Respect for other people's opinions
- ✓ Confidentiality
- ✓ Tolerance of different views
- ✓ Allow everyone a chance to speak
- ✓ Cell phones off
- ✓ Ask questions

What you want to learn (5 min)

Make a list on a large piece of paper of what the participants aim to learn from the workshop. To make sure everyone contributes suggestions use random selection (i.e. anyone wearing blue, who's name starts with 'S' etc). Participants may want to tell the group what their training or job is. This list is kept for the rest of the workshop, and will be checked and added to.

Group Body Map (15 min)

A volunteer can trace the facilitator's outline onto a piece of paper/card. One person lies down on a large piece of card and another person takes a pen and draws around their body. This can also be done by standing against a wall. Participants are then invited to add pieces of information by drawing all they know about the human body on the body map. To get things going ask questions such as:

- How do we see?
- What keeps our bodies upright?
- Where does food go when we eat it?
- What are some of the ways HIV affects the body?
- How do we feel?

Drawing the group body map is a useful way of seeing how much the group knows about the human body. It also shows everyone how to make a body map. Encourage participants to draw by making it as fun as possible - don't worry about being 100% accurate!

Getting Started

- Ask the participants to divide themselves into groups of 3 - 5 people. Each group is given a large piece of card/paper. One participant can volunteer to have the outline of their body traced. This can be done by either lying down on a sheet of paper or standing against a wall while the body is traced. (5 min)

- The group draws the face of their volunteer on their body map, adding any other features or accessories that are particular or special, such as earrings, bangles, birthmarks etc. (10 min)

Session 2

Cells as Building Blocks in the Body

- Give each group an envelope containing a picture from a magazine or newspaper that has been cut into pieces like a puzzle. Ask the group to put the image together again. (5 min)

- Ask the group if there is anything in the body similar to the parts of a puzzle. Introduce the idea that the human body is made up of billions of cells that the human eye cannot see. Cells are the building blocks of the body and are like pieces in a complex puzzle that fit together to make up the body. Ask volunteers to come and add any information they know about cells to the board. The following questions might be useful:
  - Can we see the cells in our bodies?
  - What cells have you heard of?
  - How does human life begin?
  - How do we grow? (10 min)

FACT FILE
Cells are like building blocks making up the human body. A human life begins when a mother's egg is fertilized by a father's sperm. This single cell divides itself in two, which then divides into four and so on until the body is formed. When we are children new cells create tissue and bones in order for us to grow. This process continues even once we are adults as the body continually renews itself. Our bodies are constantly making new cells to replace old ones. This is more obvious with things we can see growing like our hair and nails, but happens throughout the body.

- Make a mark with the tip of a sharp pencil on a sheet of paper and hold it up for the group to see. The human female egg is roughly the size of the mark and is the largest cell in the body. It is 85 000 times larger than a sperm. There are many things the human eye cannot see without the aid of a microscope or magnifying glass. Ask what other things the human eye is unable to see such as bacteria and viruses. (5 min)

What do cells do?

- Ask the participants what they think cells do in the body. Were they born with the same number of cells? What do cells need to live? What does DNA control? Create a list while answering these questions by asking volunteers to come up and write on the board. (10 min)

FACT FILE
Cells need food and oxygen to do their work in the body. A healthy diet helps build cells which make for a healthy body. We already know cells die and reproduce everyday in our bodies. Cells also produce chemicals that control body functions and maintain the body. Cells know what to do and how to divide because inside each one there is genetic code. This code is like an instruction manual for our bodies and is called DNA (deoxyribonucleic acid).

Skeletal System and the Skin

- Refer back to the initial body map created by the whole group and ask the group to explain how their bodies stay upright. Introduce the skeletal system using the Visual Body Map. Ask each group to choose a part of the skeleton to draw on their body map. They can add facts about the skeleton directly to their body maps:

- gives body shape and support
- consists of 206 bones
- protects internal organs and tissue (i.e. brain inside skull)
- produces blood cells in the marrow (5 min)

FACT FILE
Skin is strong, waterproof and elastic. It has sweat glands that produce sweat to get rid of waste and keep the skin cool. It has nerve endings that allow us to feel things we touch. Feeling pain is one way the body protects itself. Some special skin cells produce pigment (colouring) that provide some protection against the sun. Some cells around the eyes produce tears to keep the eyes moist and to keep them free of germs /micro-organisms.

- Why do we need skin? What would happen if we had no skin? Discuss the skin and what function it performs. Add this information to the Visual Body Map in writing. Each participant can choose a colour and trace over the contour of their body on their body map to represent skin. They can also illustrate details like tears, sweat etc. (5 min)

The Nervous System

- Light a candle and ask a volunteer from the group to hold their finger in the flame. Why do they refuse? Ask the group what happens if we put our hand near a candle flame. Discuss nerve endings in the skin as a way of introducing the nervous system using the Visual Body Map. (5 min)

- Give each participant a photocopied map of the area and ask them to find their homes, work, clinic etc. Ask participants how they got to the workshop? Did they use a taxi or a bus or a train? Ask them to draw their route getting to the workshop on the map with a colour pen. They can stick the maps onto their body maps.(10 min)

- Ask the group questions on the similarities between a map and the nervous system. For example, when we put our finger near a flame, the message of pain travels all the way to our brain, which tells us to remove our hand. Draw this 'path' from the finger tip to the brain directly on the Visual Body Map's nervous system. (5 min)

FACT FILE
Sensory nerves carry information received from the senses (i.e. sight, hearing, touch, taste and smell) to and from the brain. Motor nerves carry messages from the brain to muscles to control movement. Other nerves control unconscious actions such as breathing, digestion and keeping the heart beating.

Session 3

The Circulatory System

- Get the group to do a 'body alphabet' exercise to get them active again. Ask volunteers to call out the letters that spell their name. The group then responds by matching the shape of their body to the letter. Usually the group finds this a fun and humorous exercise. (5 min)

- Ask the group to check their partner's pulse. What is a pulse? Introduce the circulation system by showing them the Visual Body Map. The circulation system and the nervous system are similar in that they both reach all parts of the body. Refer back to the photocopied map comparing highways, roads and streets to arteries, veins and blood vessels. (5 min)

FACT FILE
Blood vessels are tubes which carry blood throughout the body. They become smaller and smaller as they form a network reaching every part of the body. Arteries carry blood from the heart to the rest of the body. Veins carry blood back to the heart. Red blood cells are like a fleet of delivery vans carrying oxygen as blood is pumped to all parts of the body. White blood cells are like a clean-up service cleaning up dead blood cells and fighting infections.

- Ask a volunteer to illustrate on the Visual Body Map how oxygen travels in the blood from the lungs to reach all parts of the body. Ask another volunteer to show how food and medication are swallowed, pass into the digestive system and then pass through the lining of the stomach and small intestine into the circulatory system. Participants can add information about the circulatory system onto their body maps. (10 min)

The Immune System

- Introduce the lymphatic system using the Visual Body Map by overlaying it on the nervous and circulatory systems. Ask what happens if we cut or graze ourselves by accident. Apart from blood what else do we see? What does it do? Apart from cuts how else can our bodies get infected or sick? How does the body fight things like 'flu'? Do a brain storming exercise on the immune system and how it heals the body including the role played by the B lymphocytes, CD4 T lymphocytes (Helper Cells) and CD8 lymphocytes (Killer Cells). (10 min)

FACT FILE

The colourless liquid that can be seen when skin is grazed or cut is called lymph fluid and is part of the immune system. Lymph fluid helps fight infection by sealing the broken skin and killing germs. Lymph fluid circulates the body in the lymph vessels and clears the body of germs and dead cells. The immune system works closely with the circulatory system. There are red blood cells (that carry oxygen) and white blood cells (that work for the immune system). White blood cells are found in the lymphatic system, body tissues and blood. We cannot see them as easily because they are not as many as the red blood cells. There are different kinds of white blood cells, including those known as lymphocytes. (cytes = cell, lymphatic system = lympho). B Lymphocytes (B cells), CD4 T Lymphocytes (helper cells or CD4 cells) and CD8 Lymphocytes (Killer cells or CD8 cells) are a vital part of the immune system.

- Hand out 4 balloons (different colours if possible) to volunteers and label them CD4 T-Lymphocyte (CD4 cell or Helper T-cell), CD8 T-Lymphocyte (Killer T-cell) and B-lymphocytes (B-cells). Make sure to draw the receptors on the CD4 cell. Label the last balloon as a ‘flu’ virus. (5 min)

- Ask the volunteers to act out the different functions of the immune system when a ‘flu’ virus invades. Each person has to introduce the cell they represent and what its functions are. Secretly give the person representing the B-cell a pin to pop the ‘flu’ virus balloon at the end to show how the immune system is able to beat the ‘flu’ virus. The rest of the group can call out and tell the actors what to do. Keep the labelled immune system balloons. (15 min)

FACT FILE
When the ‘flu’ virus enters the body it travels in the blood stream. The CD4 cell is the first to notice it and sends messages to the rest of the immune system to come and help get rid of it. The CD8 Lymphocytes directly touch and destroy the viruses. When B-cells find a virus they react by producing antibodies that attach to the virus so that the white cells can destroy them. This process takes a bit of time (usually 2 weeks for ‘flu’) and a person only gets well once all the viruses have been destroyed.

Session 4

How to Prevent HIV Infection

- Ask the group if any of them had ‘flu’ during the past winter. The purpose of this exercise is to look at how viruses are transmitted. It introduces the idea that there are different ways for a virus to enter the body and we are able of protecting ourselves from infection. Ask the following questions to generate some discussion.

- How do they think they got the ‘flu’?
- Can someone give you ‘flu’? How? Why?
- Is there anything you can do to prevent yourself from getting ‘flu’?

(5 min)

- Ask the group how HIV enters the human body. Get participants to mark those places on their body maps where HIV can enter the body. They can mark it with an ‘x’ or they can draw it. Depending on the group, their age and cultural background there might be embarrassment when drawing sexual organs. In these cases an ‘x’ avoids this problem. Participants write next to each area to explain how the virus enters the body in these places. (10 min)

FACT FILE
Unprotected sex is the main cause of the HIV infection in South Africa. HIV can also be transmitted through open cuts and wounds, car accidents, blood transfusions, shared needles and mother-to-child transmission. HIV is present in infectious quantities in blood (including menstrual blood), semen and pre-ejaculate, vaginal and cervical secretions, wound secretions, amniotic (pregnancy) fluid and breast milk. Very low secretions are found in saliva, sweat and tears. HIV is not normally present in urine, faeces and vomit, unless there is also blood present.

- Test the group's comprehension of ways of transmission by asking questions like 'Can you get HIV from sitting next to someone?' etc. Ask the group to call out all the ways a person cannot get HIV such as hugging someone, sharing cooking utensils etc. while one or two participants write up a list on the board in front of the group. (10 min)

- Discuss ways the group can protect themselves from getting infected or potentially infecting others. Add the preventative measures they can take next to each area they have marked with an 'x' on their body map. If the workshop is being used in a support group with people who are HIV-positive, this knowledge is also important for them. They can avoid passing on the virus to future children born to them, they can prevent being re-infected with different strains of HIV or infecting future sexual partners and they can be a source of knowledge for people in their community. In this way they could prevent their children, family and friends from getting HIV if they share this knowledge. (10 min)

FACT FILE
Both male and female condoms help prevent HIV transmission. Even if both partners are HIV-positive, they still need to use condoms so they do not re-infect each other with different strains of HIV. As HI viruses reproduce in the body there are slight mutations (changes) in the virus. This means that HIV is constantly changing in the body, developing different strains (kinds) of HIV. This does not mean HIV-positive women and couples cannot have children. If

someone wants to have a child, they should discuss the options available with their clinic or doctor. HIV-positive people can have children, but they need to take extra care with their health and can prevent infecting their baby by taking antiretroviral drugs to prevent mother-to-child transmission.

Social Challenges and Solutions

The following exercises aim to encourage debate and acknowledge that HIV/AIDS is also connected to social and economic conditions that can make it difficult for individuals to make the best decisions about their health. It also aims to give workshop participants some practical solutions.

- As a group discuss how living conditions can contribute to the spread of HIV/AIDS. A volunteer can write a list on the board of possible topics which might include:

- poverty
- high unemployment levels
- migrant labour
- transactional sex in exchange for food, school fees etc.
- living conditions in informal settlements
- alcoholism and drug abuse
- rape
- violence (5 min)

- Once the list is complete, participants can discuss possible solutions to some of these social and economic challenges. This could also include practical steps such as using Social Services to access grants or contacting other organisations such as the AIDS Law Project, support groups in your area etc. This exercise can also serve as a way of the participants sharing their knowledge. (10 min)

Session 5

Social Support

The different kinds of support people get from family, friends, partners and the greater community play a very important part in their lives. The decisions people make about their health often depends on whether or not they feel supported. This is why it is important to encourage people living with HIV to access as much support as they can so they are free to make the best decisions about their health.

- Get participants to discuss in pairs or in their groups all the people in their lives who give them support. This includes emotional or financial support, looking after children, providing meals, help with cleaning, advice etc. On a piece of paper participants list all the people who support them. The list can include family, people from church or another social group, a treatment buddy, a teacher, a friend from a sports team, a work colleague etc. (10 min)

- Each participant draws an outline around one of their hands on their group body map or on a piece of paper and writes the names of all the people and places that support them in the shape of their hand. (10 min)

Talking about Disclosure

The aim of this exercise is to introduce the issue of disclosure for people living with HIV. The facilitator should be sensitive to the possibility that within the group there may be people who are HIV-positive. This exercise should encourage conversation and create awareness around the issues of support and how disclosure of HIV-positive status can affect relationships and families both positively and negatively. The emphasis is on disclosure as a way of accessing different kinds of support from family, friends and sexual partners.

- In their groups the participants discuss what advice they would give to someone who is HIV-positive and wants to disclose to someone close to them. The following suggestions have been made by HIV-positive people who know what it is like to disclose their status.

- Accept your HIV-positive status first before telling anyone.
- Think it through carefully, imagining the kind of questions the person might ask.
- Prepare yourself mentally and emotionally for any unsupportive words or actions.
- Attend support groups where you can get support from other HIV-positive people.
- Choose someone in your support group to be a friend - someone you can call when you need to talk to someone.
- Don't stay alone - keep busy and active.
- Choose your friends carefully – you don't have to tell everyone.
- It might be easiest to disclose to your family first, because they will stand by you.

- Telling your partner is important if you care for them and want to prevent infecting them. But sometimes the risks are highest when disclosing to your partner, because they might accuse you of cheating on them and bringing the disease into the relationship. Or you might be financially dependant on them. One solution is to go and get HIV tested together and learn your results together.
- If someone knows in advance that you are HIV-positive they can help you should you fall ill. They can also start to learn about the virus and give you support. (10 min)

- In pairs ask the participants to role-play or discuss potential situations HIV-positive people might encounter in real life when disclosing their status. Examples include telling a parent, a sister, a sexual partner or a friend. Ask the participants to include both positive and negative responses and to discuss how someone might best prepare themselves for potentially unsupportive responses. (15 min)

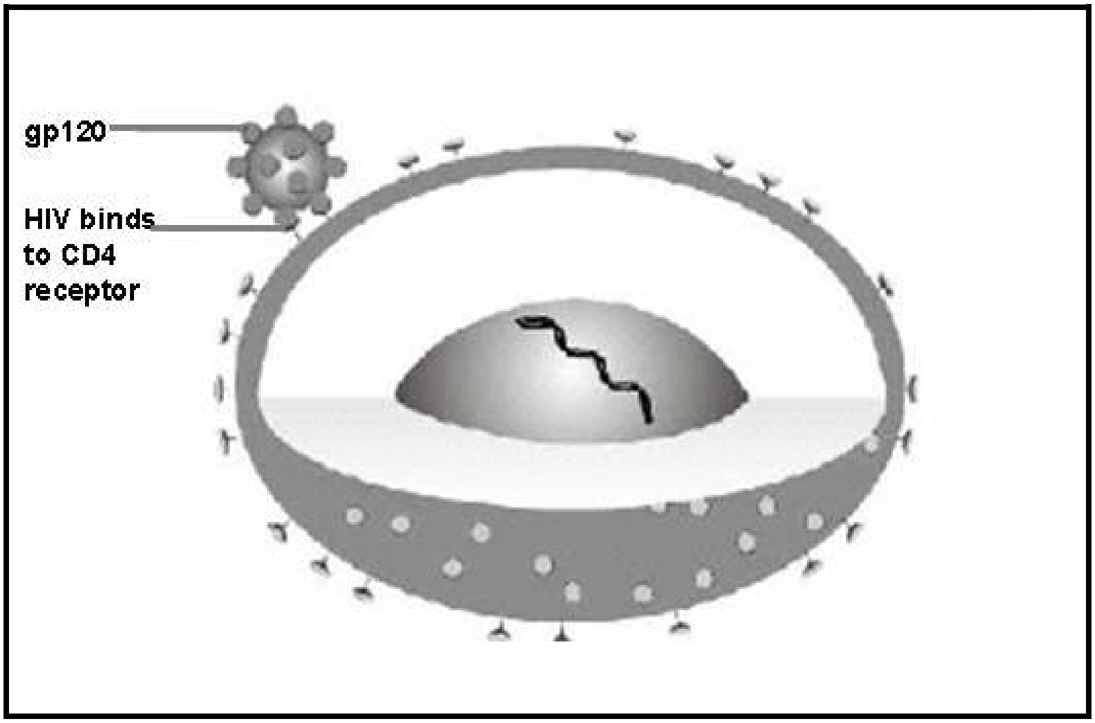
Session 6

What happens when HIV enters the body?

FACT FILE

Like all viruses, HIV has only one purpose and that is to multiply. It cannot multiply outside the human body because it needs human cells to replicate (reproduce or multiply). The HI virus needs DNA in order to multiply, but it does not have its own DNA so it enters the CD4 cell and uses the CD4 cell's DNA to reproduce. Once inside the CD4 cell it is also safe from antibodies (created by the B-cells), as well as killer T-cells. The HI virus releases its instructions (RNA) into the CD4 cell together with other enzymes called reverse transcriptase and protease. Reverse transcriptase enables the RNA to become pro-viral DNA which can then fit into CD4 cell's DNA. This makes the CD4 cell start producing HI viruses instead of more CD4 cells.

- Ask a volunteer to draw a CD4 cell on the board. Make sure the CD4 cell has receptors clearly drawn. Ask another volunteer to draw an HI virus illustrating its unique shape and how it attaches itself to the CD4 cell. (10 min)

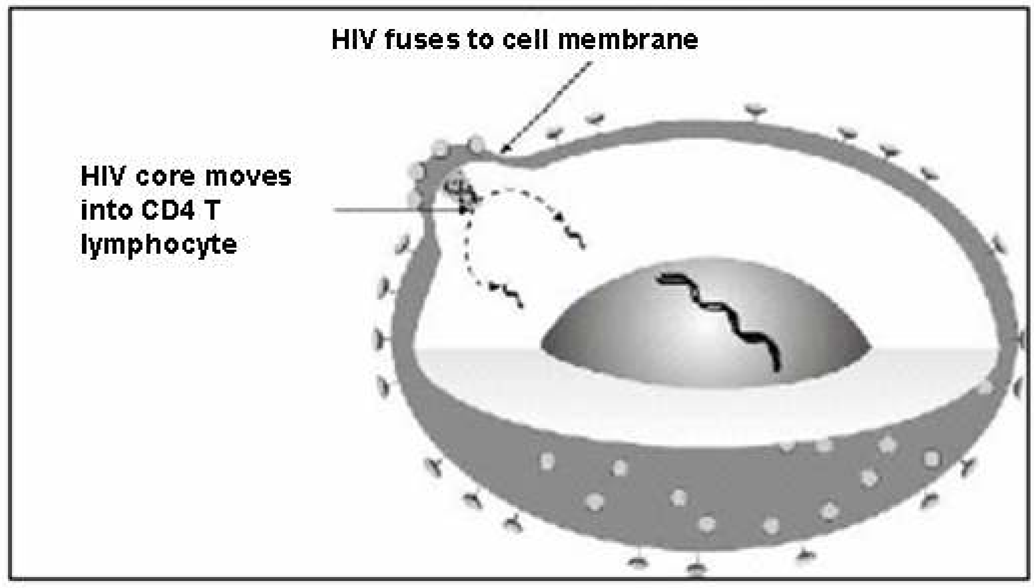


- Show the participants a lock and keep the key in your pocket. Ask if anyone has keys with them. Call on volunteers to come forward and try to unlock the lock with their keys. Ask the group why they are unsuccessful. On their prompting use the key in your pocket to open the lock. Use this example to illustrate the way the bumps (gp 120) on the HI virus lock with CD4 receptors. (10 min)

What happens when HIV enters the CD4 cell?

- Ask volunteers to add to the drawing and show the steps involved as an HI virus enters a CD4 cell. Ask and answer questions to clarify the process:

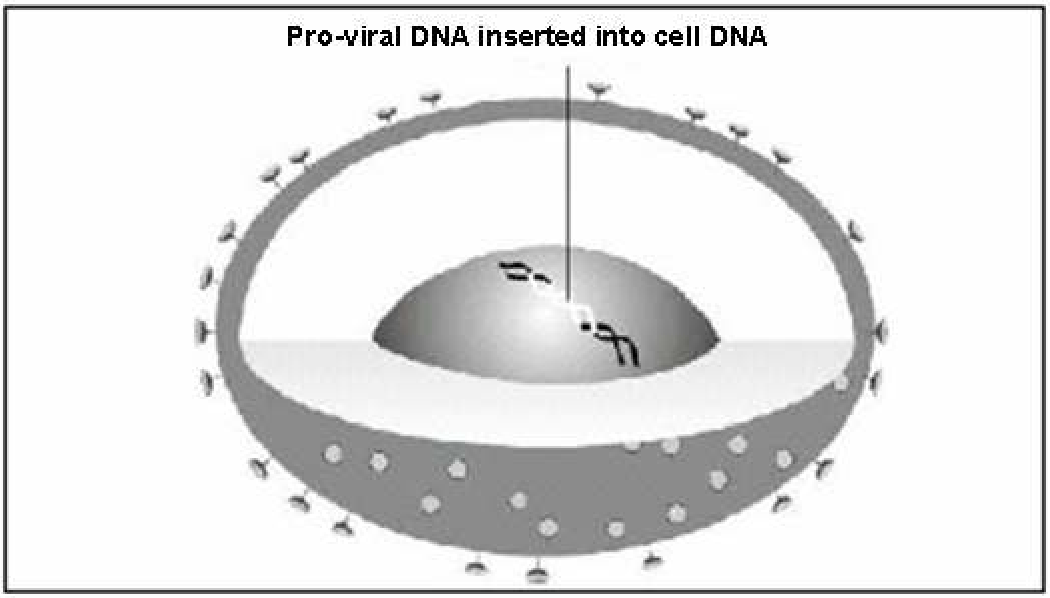
- Why does the HI virus enter the CD4 cell?
- What does it want to do once it is inside the cell?
- What does it need to reproduce?
- What does the HI virus release into the cell?(10 min)



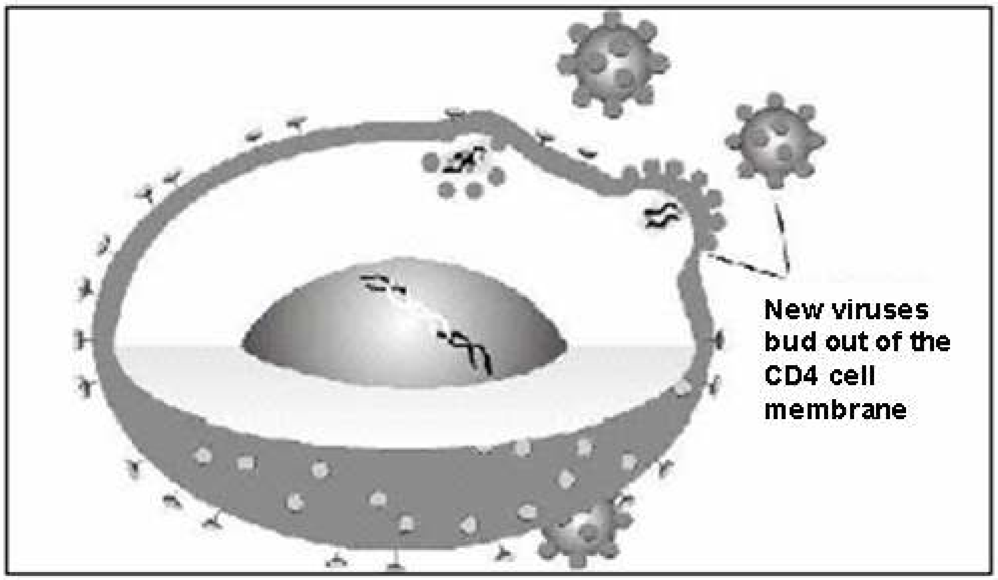
- Use a zip to illustrate how the reverse transcriptase transforms the RNA to match the CD4 cell's DNA. One side of the zip can be likened to the CD4 cell's DNA. The other side of the zip can represent the HI virus's RNA, which is made to fit or lock with the DNA with the aid of the reverse transcriptase. Ask volunteers from the class to come and explain the process using the zip. (10 min)

FACT FILE

Once the HI virus has control of the CD4 cell's DNA, it becomes part of the CD4 cell and uses the CD4 to make new HI viruses. Protease is responsible for organizing the building of the new HI viruses. These new HI viruses are released from the CD4 cell back into the blood stream where they attack more CD4 cells. Once an HI virus has taken over a CD4 cell and used it to make more HIV, the CD4 cell dies. As more HI viruses are reproduced and released into the blood stream, fewer and fewer CD4 survive. Eventually there are so few CD4 cells that the immune system cannot work properly and will be unable to fight infections.



- Discuss the differences between a 'flu' virus and an HI virus with the group by asking questions such as:
  - What does the HI virus do that a 'flu' virus cannot do?
  - What is special about the shape of the HI virus?
  - Why does HIV enter the CD4 cell?
  - Can the immune system beat the 'flu'?
  - Can the immune system beat HIV? Why not? (10 min)



- Call on volunteers to represent the CD4, CD8 and B-cells in the immune system using balloons. One volunteer can represent an HI virus. Ask the group for comparisons between the immune system's responses to HIV and a 'flu' virus. It is very important that participants are able to explain why the immune system cannot successfully beat HIV infection. Once the group has clarified the differences between a 'flu' virus and HIV, the volunteers can act out how the immune system is incapable of successfully beating HIV using the balloons, but no pins this time round. (10 min)

Session 7

Opportunistic Infections

- Ask the groups to return to their body maps and think of all the opportunistic infections or other health related issues related to HIV they know of. As a group they can then label the parts of their body maps affected by specific opportunistic infections. (10 min)

FACT FILE

An HIV-positive person is more likely to get ill because their immune system is not able to fight infections. These illnesses are known as opportunistic infections. Common opportunistic infections include TB (Tuberculosis), thrush, shingles and PCP (Pneumocystis Pneumonia) among others. Many of these infections affect people who are HIV-negative as well, but they are less likely to get them because their immune system can protect them better. When someone falls ill with any of these infections they should visit a clinic immediately and get treated. If someone's CD4 count is very low, they may by given antibiotics as a prophylactic to prevent an opportunistic infection before it occurs.

- Once they finish identifying various infections and illnesses related to HIV and AIDS, call on each group to call out the names and describe the symptoms. The Fact File on pg 23 lists the most common opportunistic infections and treatments. Participants can write the relevant medication and treatment options available for each infection. Encourage the discussion of 'home remedies' and traditional medicine, as well as medication available at clinics and hospitals. Some symptoms such as rashes, diarrhoea and thrush can be treated effectively with home remedies if they are not too serious. (10 min)

FACT FILE

If a person is HIV-positive they are at greater risk of getting opportunistic infections because their immune system is weakened. It is different for each person. Here are some of the most common opportunistic infections.

Tuberculosis (TB) – TB is a bacterial infection treated with a combination of different drugs. If someone is treated for the first time they will need to take medication for 6 months. It is very important that they finish the full course to prevent developing multidrug resistant TB (MDR-TB).

- ***Thrush (oral candidiasis)*** is called by a fungus and infects the mouth and throat. If the infection is in the mouth, *nystatin* lozenges or liquid can be used. *Amphotericin B* lozenges or *miconazale* gel can also be used. *Fluconazole* is used when the infection is in the throat.
- ***Diarrhoea*** is caused by a number of parasitic and bacterial infections and can cause severe dehydration and weight loss. Depending on what is causing the diarrhoea, different antibiotics are used. Bacterial infection can be treated with *cotrimoxozole* or *doxycycline*. Some parasitic infections are treated with *metronidazole*. Drugs such as *loperamide* and *codeine* can help control the diarrhoea and water mixed with sugar and salt can be drunk to rehydrate.
- ***Pneumocystis Carinii Pneumonia (PCP)*** – PCP is a life-threatening and preventable lung disease. PCP can be treated and prevented by taking *trimethoprim* and *sulfamethoxazole* also known as *co-trimoxazole*.
- ***Skin problems*** are caused by a number of germs and can result in rashes, bumps, scales and itching. Most of the time a cream or liquid treatment is used.
- ***Kaposi's Sarcoma (KS)*** is a kind of cancer that causes dark red or purple patches on the skin and can spread to other organs in the body. Radiation therapy and chemotherapy is used to kill the cancer cells.
- ***Toxoplasmosis*** is a disease that affects the central nervous system (the brain) and sometimes the eyes and lungs. Treatment includes taking 3 drugs (*Pyrimethamine, Folinic Acid, Sulfadiazine*) for 6 weeks, and then usually for continued for life. Like PCP, *co-trimoxazole* is the most effective prophylaxis.
- ***Cryptococcal Meningitis*** is an infection of the spinal cord and brain caused by a

fungus. It is treated with a drug called *fluconazole* and will need to be continued for life to stop the infection returning.

- ***Genital Herpes*** is an STI caused by the *herpes simplex virus* or HSV. There is no cure for genital herpes but it can be treated with one of the drugs *Acyclovir, Famciclovir* and *Valacyclovir*.
- ***Vaginal Candidiasis (Thrush)*** is caused by a fungus and is treated with the drugs *Clotrimazole* or *Fluconazole*.
- ***Syphilis*** is an STI caused by a bacterial infection. It is usually treated with penicillin.

Keeping Healthy

- Call on volunteers to come forward and write up a list of all the ways people, regardless of their HIV status can keep their bodies healthy and strong. Suggestions might include a healthy diet, how to prepare foods to retain their nutritional value, keeping warm, keeping the house clean etc. (5 min)

- Hand out shop advertisements of foods. Ask participants to cut out those foods they think are important to eat and stick them onto their body maps. A healthy diet helps cells to repair themselves, as well as boosting the immune system. Poor nutrition makes us more vulnerable to HIV and other opportunistic infections. (10 min)

- Eating healthily doesn't mean that food has to be expensive. Ask the groups to discuss nutritious meals that are inexpensive to prepare. Also discuss ways of cooking food to ensure that the vitamins remain in the food. For example, not boiling vegetables, but rather making stews or using the water that has been used to boil the vegetables to make soup. The groups can then write up menus for each day in the week on a piece of paper and stick it to their body maps. (10 min)

FACT FILE
Some examples of inexpensive and nutritious foods are:
Fresh fruit and vegetables, maize meal, samp, soya mince, beans and lentils, rice, potatoes, tinned sardines or pilchards, oats, brown bread, chicken livers, peanut butter and oats.

It is important to eat a variety of foods including protein (meat, chicken, fish, eggs, beans, peas, lentils), fruit and vegetables, grains (bread, pasta, rice, sorghum, maize, oats) and dairy products (milk, *amasi*, cheese, yoghurt).

What foods to avoid:

- ✓ Too much greasy or fatty foods, coffee, salt, sugar and sweets.
- ✓ Processed and refined foods are high in sugar, salt, fat and artificial additives and have less fibre and nutritional value.
- ✓ Alcohol and tobacco
- ✓ Drinking tea and coffee with meals reduces the body's absorption of iron

- Hygiene is important for everyone's health, but it is especially important for preventing opportunistic infections if someone is HIV-positive. Call on volunteers to come up and compile a list. Some hygiene tips could include:

- Wash hands before food preparation and after going to the toilet.
- Clean the home regularly and keep it well aired.
- Fresh foods should be washed before cooking.
- Water should be boiled if it is unsafe (contains harmful bacteria).
- Meat should be refrigerated or bought fresh before cooking.
- Jeye's fluid, Jik (bleach) or Detol are all useful disinfectants that can be used in the house. (10 min)

- Cut-outs of advertisements or drawings of cleaning products can also be added to the body maps along with written explanations. (10 min)

FACT FILE
Guidelines for home-based care:

- ✓ Avoid skin contact with body fluids and open wounds, sores and breaks in the skin. If you have a cut, make sure it is dressed and covered with a watertight material (i.e. latex gloves).
- ✓ When cleaning blood spills and soiled clothing and bedding, use latex gloves or plastic bags to prevent infected blood touching the skin.
- ✓ Place clothing or bedding in a strong solution of bleach for 30 minutes and then wash in usual way.
- ✓ Mop hard surfaces with hot water and soap and wipe over with strong solution of bleach.
- ✓ A break in the skin accidentally exposed to HIV should be rinsed with running water. Visit the clinic for post-exposure prophylaxis (PEP).

Session 8

How to find out if you are HIV-positive

- Encourage the groups to discuss the things that prevent people from getting tested. Ask them to come up to the board and make a list. This could include previous bad experiences at the clinic, fear of discovering they are HIV-positive and not knowing what to do next, fear of medicine and hospitals etc. (5 min)

FACT FILE
One way of finding out your HIV status is to go to a clinic for Voluntary Counselling and Testing (VCT). Most tests require that a little bit of blood is taken. The most common tests (i.e. ELISA or rapid tests) check to see if there are HIV antibodies present in the blood. When a virus enters a human body, the immune system (B cells) creates antibodies to fight the virus. If there are HIV antibodies in the blood, it means that HIV must be inside the body. The immune system takes a bit of time to fight a virus. The time gap before there are enough antibodies to be detected by a test is called a ‘window period’. This is why it is important to return for re-testing after three months.

- Two volunteers can do a role play exercise in front of the group where one person can pretend to go to the clinic and ask a nurse or community health worker how they can find out if they are HIV-positive. The group can call out advice including how and where to get tested, the advantages of knowing your HIV-positive status before you get seriously ill etc. Alternatively this can be discussed in groups. (10 min)

Monitoring your health if you are HIV-positive

- Once someone knows they are HIV-positive it is important they monitor their health. In particular they need to watch the immune system closely to see how it is coping. Ask the group how an HIV-positive person can do this? Answers might include:

- Regular visits to the clinic
- Prophylactic use of antibiotics to prevent opportunistic infections
- CD4 count and Viral Load tests (5min)

FACT FILE
A viral load test counts the number of HI viruses in the blood. This is mainly used with HIV-positive patients to see if they need antiretroviral treatment or to monitor how well treatment is working. When someone is on antiretroviral treatment, an increasing number of HI viruses (viral load) shows treatment is not working. This can mean the person is not taking their treatment properly or that they have developed drug resistance and their body no longer responds to the antiretroviral treatment. In this case they will need a different drug. This can happen if a patient does not take their medication correctly. With successful treatment the HI virus can become undetectable in the blood. This does not mean the person no longer has HIV. They still have the HI virus in their body, but their immune system is strong enough to control it from multiplying. Viral load is calculated by counting the number of HI viruses in a cubed millimeter of blood (mm^3).

A CD4 cell count test counts the number of CD4 cells in the blood to see how healthy a person’s immune system is. This test can be used to monitor how well a patient’s body is responding to antiretroviral treatment or decide when to use medication that prevents or helps fight opportunistic infections. If a person’s

CD4 count is very low (below 200) they are often given antibiotics to prevent disease before it occurs. A CD4 count can also help decide when to start antiretroviral treatment. CD4 count is calculated by counting the number of CD4 cells in a cubed millimetre of blood (mm^3).

- CD4 count and viral load tests are particularly useful ways of measuring how the immune system is coping. Divide the group in two and let one group ask questions to test the other groups' understanding about viral load and CD4 count tests.

How are these tests measured?
Why is it important to do these tests?
Why are CD4 cells counted and not other kinds of cells?
How do they do the tests?
Why is it important to return to the clinic for check-ups even if you are not on treatment? (10 min)

Stages of HIV/AIDS

- Ask if the group has heard of the different stages of HIV as it progresses towards AIDS. Draw a timeline showing the four stages. Mark the level of the CD4 count resting at 200 as illustrated (pg 29). Choose one colour to represent the CD4 count and another colour to represent the viral load. Ask two volunteers to draw what they think happens to the CD4 count and the viral load as the disease progresses without antiretroviral treatment. Make any necessary adjustments and add any other information the group might know about the different stages. (10 min)

Stages of HIV Infection

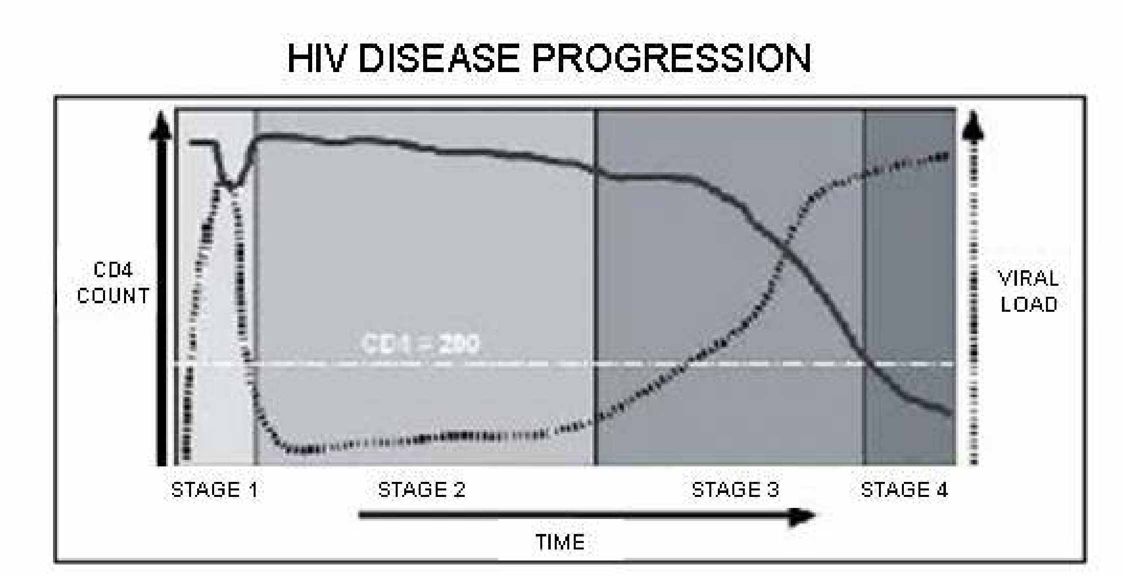
In the first stage, the HI virus has just entered a person's body and starts to replicate (multiply). The HIV antibodies cannot be detected in the blood yet and so this is often called the window period and can last from three to twelve weeks. During this time the person is still infectious. Four to sixteen weeks after infection the person's HIV status will change from negative to positive (seroconversion). Some patients may have 'flu-like' symptoms, but otherwise appears well and can remain so for many years.

In Stage 2 the immune system starts to be overwhelmed by the HI virus and will start to get infections and symptoms. The CD4 count decreases while the viral load increases.

Stage 3 means that the immune system continues to deteriorate and the person gets weaker and experiences more infections and illness. The CD4 count continues to drop while the viral load increases.

Stage 4 is when the person is said to have AIDS. The immune system can no longer work, since the CD4 count is very low and the viral load is very high. The person is seriously ill and is often in bed.

The way HIV affects our bodies differs from person to person. If we are healthy it might take our body a long time to show signs of struggling to fight infection. That is why many people can live for years and not realize they are HIV-positive. The way HIV affects the human body has been broken up into different stages to help doctors monitor the virus and how it affects our bodies.



What does Antiretroviral Treatment do?

- Refer back to the drawing completed earlier of HIV entering the CD4 cell. Ask a volunteer to draw over it to show the stages in the production of HIV that antiretroviral treatment halts. Even if the names of reverse transcriptase and protease are not used, the emphasis is on understanding that treatment prevents more HI viruses from being produced. (5 min)

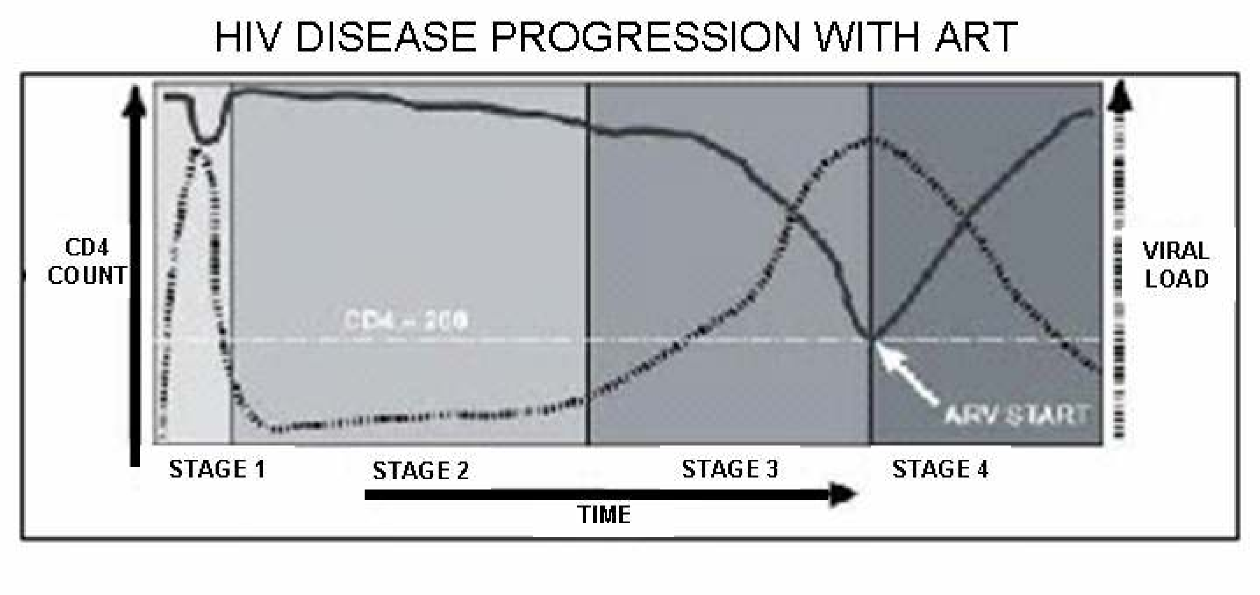
FACT FILE

Antiretroviral (anti = against, retroviral = retroviruses like HIV) drugs prevent or slow down the production of the HI virus by blocking the action of the reverse transcriptase and protease. By stopping the production of more HI viruses, antiretroviral treatment helps the immune system by reducing the viral load (number of HI viruses in the blood), as well as preventing further loss of CD4 cells. When doctors first started giving HIV-positive people treatment only one drug was used, but it did not stop all replication of HI viruses. When the virus mutates it becomes resistant to the treatment and is able to continue reproducing. Now doctors usually use a combination of three different antiretroviral drugs to slow down the rate the HI virus reproduces. It is called HAART (Highly Active Anti-Retroviral Therapy). To stop HIV from replicating there needs to be the right amount of antiretroviral drug in the patient's blood stream all the time. To make sure that there is the right amount 24 hours a day the drugs must be taken in the right amount, at the right time every day.

- Participants return to their body maps and draw the path the drugs take from the mouth, down the throat into the stomach and then the blood stream. Any other information such as the names of specific regimens can be added to the body maps as well. (5 min)

- Bring out the drawing of the different stages of HIV that was used to describe how CD count and viral load tests are used to monitor the health of someone who is HIV-positive. Ask the group at what stage someone usually goes onto antiretroviral treatment. Mark the point on the chart where the CD4 count reaches 200. Ask for a volunteer to come and alter the drawing to show what antiretroviral treatment does to the CD4 count and viral load as seen on pg 30. Ask them to explain as they draw. (10 min)

Session 9


HIV DISEASE PROGRESSION WITH ART

How to Prepare for Antiretroviral Treatment

- Ask volunteers to compile a list of all the things a person needs to know before they go onto antiretroviral treatment. Make sure the following are covered:

- When you find out you are HIV-positive you don't need to go onto antiretroviral treatment immediately, unless your CD4 cell count is less than 200, or you are diagnosed with a Stage 4 defining illness.
- You have to be willing to go onto antiretroviral treatment before it is prescribed.
- ARVs are for life. You cannot stop taking them when you feel better.

- You must be prepared to disclose your status to at least one person who you are living with or a 'treatment buddy'.
- It is very important to attend clinic appointments regularly.
- If you have other illnesses like TB, pneumonia or diarrhoea you might have to wait until you are string enough before starting treatment.
- If you have a problem like depression, alcohol or drug abuse, treatment might have to wait until you are well again.
- A home visit might be necessary to see what support you will get at home or if help is needed (such as food parcels etc).
- ARVs do not reduce the risk of passing the HI virus to other people, so use condoms or abstain even if you are married.
- Do not share your ARVs with other people.
- Go to the clinic as soon as possible if you are ill or have any side effects from the ARVs.

(10 min)

Antiretroviral Treatment Options

There are a number of different antiretroviral treatment options. Like many other medications, antiretroviral therapy has specific instructions of when
and how to take the pills and there can also be side effects.

- **D4T, 3TC, Efavirenz**

Store in a cool, dry place.
Take one tablet of D4T and ATC in the morning and in the evening take one tablet of D4T and ATC and 3 Efavirenz.
Don't drink alcohol when on this treatment.
Possible side effects are fever, diarrhoea or stomach problems, dizziness, loss of appetite, tiredness or weakness, trouble sleeping, mild depression, some hair loss and shift in body fat location.

- **AZT, 3TC, Nevirapine**

Store in a cool, dry place (Do not freeze).
Take one of each tablet morning and night.
Don’t drink alcohol when on this treatment.
Possible side effects are fever, mild stomach problems, nausea, dizziness, loss of appetite, headaches, cough, tiredness or weakness, trouble sleeping and shift in body fat location.

- **AZT, DDI, Kaletra**

Store AZT and DDI in cool, dry place.
Store Kaletra in the fridge and use within 2 months.
Don’t drink alcohol.
Take 4 DDI tablets on an empty stomach 30 minutes before breakfast with a full glass of water.
Take 3 Kaletra tablets with food in the morning and evening.
Take 1 AZT tablet morning and evening.
Possible side effects are fever, mild stomach problems, nausea, dizziness, loss of appetite, headaches, tiredness or weakness, trouble sleeping, changes in how food tastes, discolouration of nails and shift in body fat location.

- **D4T, 3TC, Nevirapine**

Store in a cool, dry place.
Don’t drink alcohol when taking this treatment.
Take one tablet of each both morning and evening.

Possible side effects are fever, mild stomach problems, cough, dizziness, loss of appetite, headaches, tiredness or weakness, trouble sleeping and shift in body fat location.

A person taking antiretroviral therapy should visit their clinic as soon as possible if they experience any side effects or unexplained changes in their health and body. These can include skin rash, sores in the mouth, irritated eyes, swelling, difficulty breathing, nausea, vomiting, stomach pain, diarrhoea, tiredness, yellow skin or eyes, dark urine, strange coloured stools, burning or numbness or tingling in the hands, arms, feet and legs, and joint and muscle aches.

- Ask volunteers to come forward and list all the different treatment options they know, along with information such as storage and how and when to take the medication. The facilitator may need to check with the Fact File section on page 31 and 32. (10 min)

- In their groups participants can mark, label and describe all the possible side effects from each of the antiretroviral treatment combinations on their group body maps. Once again the Facilitator may need to refer to the Fact File information. (10 min)

Adhering to Antiretroviral Treatment

- Divide the group into two to discuss what often stops HIV-positive people from going on antiretroviral treatment. Each group should create a list of all the things they think prevent or make it difficult for people to access treatment. The following list was created by HIV-positive people who are on antiretroviral treatment.

- fear that the medication is harmful to their body (toxic)
- fear of side effects
- difficulty of taking the medication twice a day at the same time each day
- knowing that they will have to take the treatment for the rest of their lives
- having to prepare food before they can take some of the treatment
- needing to disclose to people you live with
- afraid of being seen taking treatment and then having people ask questions or gossip about you
- denial of being HIV-positive
- living in a remote area where the nearest treatment centre is far away
- fear of violence if they disclose their HIV-positive status
- money for transport to get to the clinic (10 min)

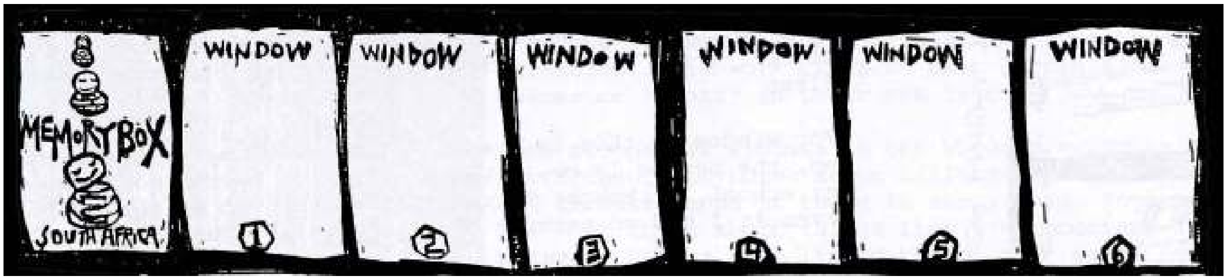
- Ask the groups to swap lists. Now each group can discuss and write down solutions or ways of assisting someone who has the difficulties described in the list they have been given. This can also be done as one large group. The following suggestions made by HIV-positive people.

- attending a support group where they can get support and also learn more about HIV
- receive education about HIV so that they can understand how treatment works - in clinics or support groups or peer education
- read pamphlets
- watch ‘Beat it’ and ‘Soul City’ and other programs about HIV/AIDS
- choose a treatment supporter or ‘buddie’
- making a close friend in their support group, someone they know they can phone at any time
- use pill boxes to help take the treatment at the right time
- set a reminder on their cell phone when to take their treatment
- speak to a social worker or someone at the clinic if they need food parcels or apply for a social grant if you are eligible
- join a group such as TAC or other community or activist groups
- spend time with other HIV-positive friends who share your experiences
- don’t stay alone, keep busy (10 min)

- Ask the group to think of a slogan for their body map. Each participant can create a personal slogan that expresses what they believe or think or feel. It may have to do with their stand against HIV/AIDS or an unrelated philosophy or attitude to life. They then write their slogan on their body map. (5 min)

- In closing take out the list of things the group wanted to learn in the workshop and check that everything has been covered. Use this time to answer questions, clarify anything that may have been misunderstood etc. Finally thank the group for their time and commitment. (5 min)

Appendix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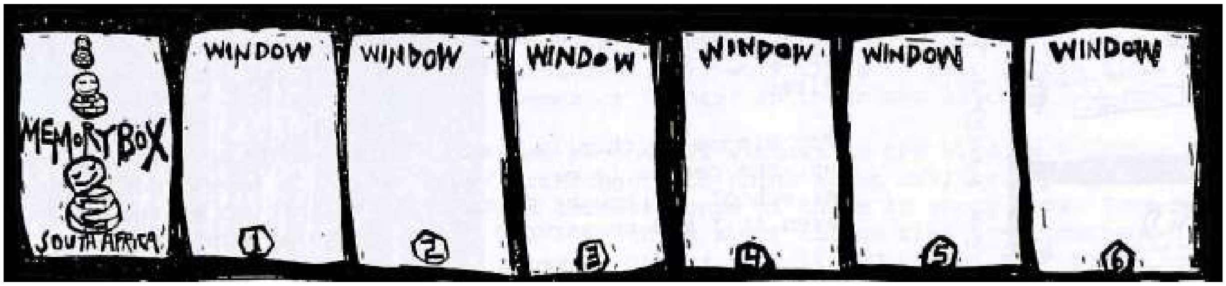
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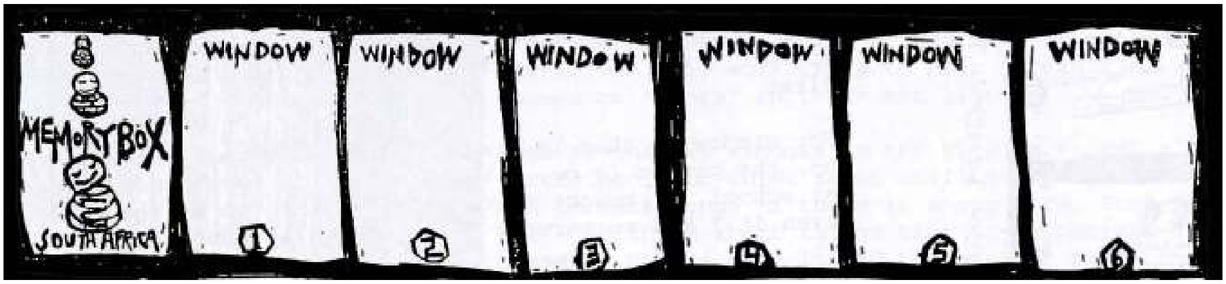
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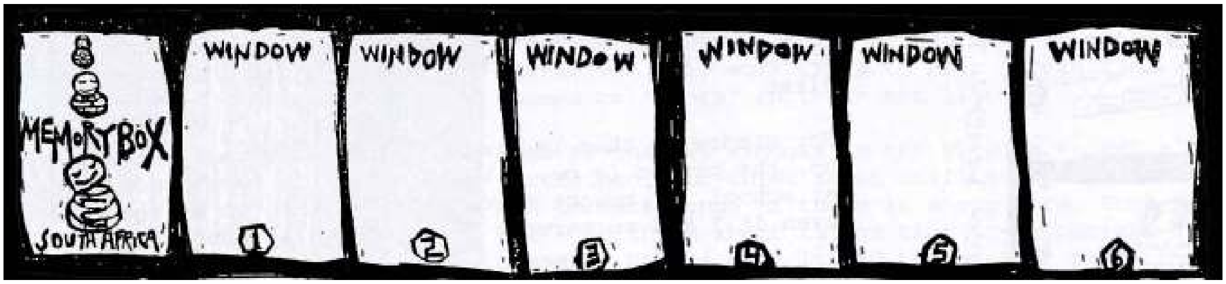
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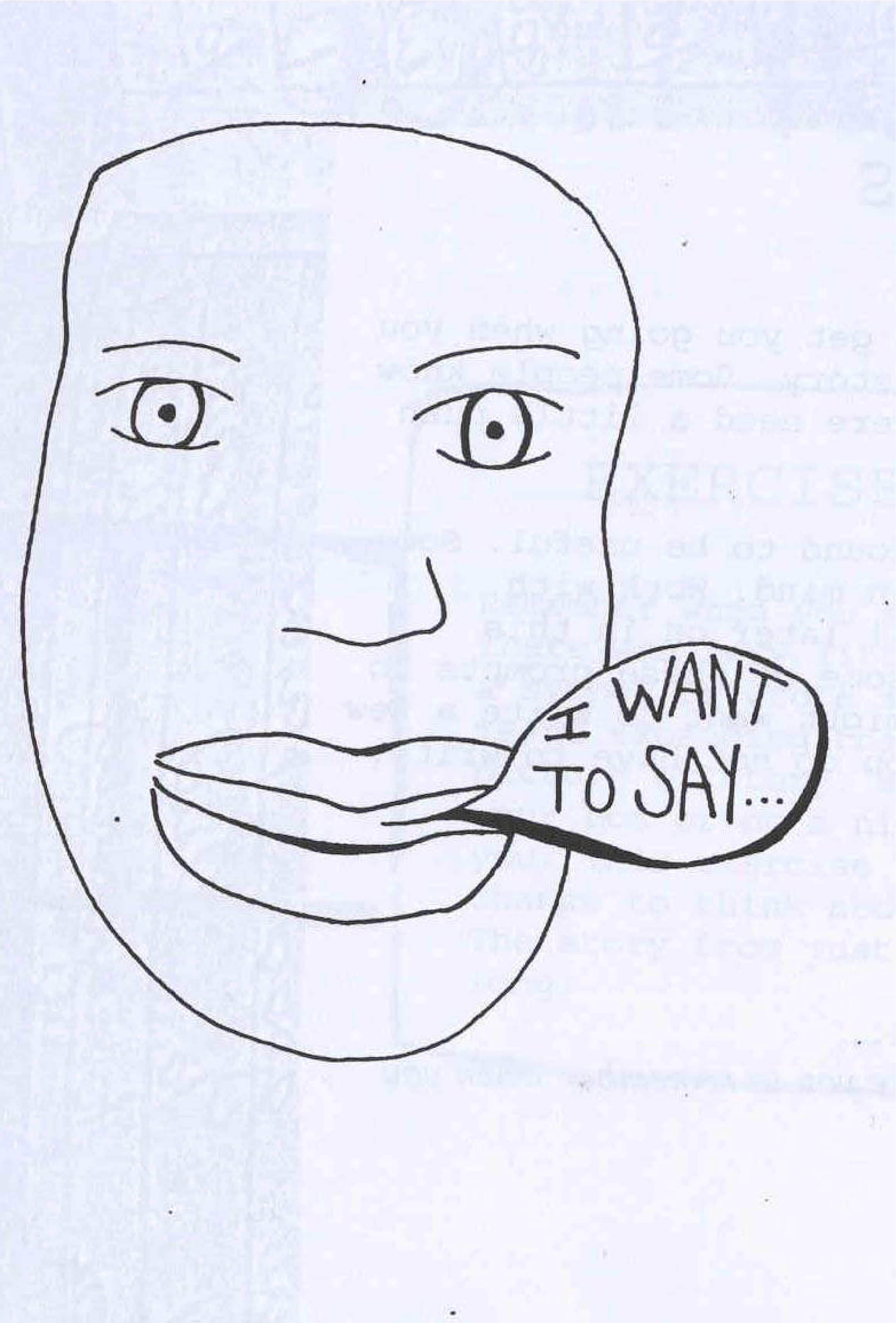
I WANT TO SAY...