

PSYCHOSOCIAL WELLBEING SERIES

Memory Work Manual

FACILITATOR'S GUIDE



Psychosocial Wellbeing For All Children



International Federation
of Red Cross and Red Crescent Societies
Southern African zone

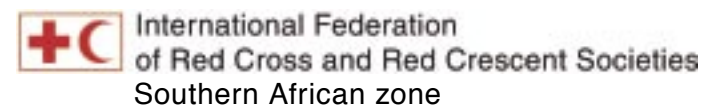
This manual began as the work of Jonathan Morgan in 1999, inspired by the work of the NACWOLA women of Uganda. It has been a collaborative effort spanning 8 years with critical contributions from the following people: Jennifer Inger, Patricia Nyabadza, Anya Subotzky, Lisa Stratton, Kylie Thomas. For a full list of contributors, see page 45.



Psychosocial Wellbeing For All Children

Integrated across and into a continuum of psychosocial care and support model for psychosocial wellbeing, REPSSI as the host agency for the Ten Million Memory Project has been actively developing knowledge around life story, narrative and memory approaches for half a decade. Through robust dialogue with academics, research institutions and communities affected by HIV and AIDS, poverty and conflict, we continue to strive to ensure that this work is evidence based, and never offered as a stand alone or 'quick fix' short term approach or that it supplants or undermines community strengths. Throughout the development process around this work, The Red Cross Societies of southern Africa, through the International Federation of Red Cross and Red Crescent Societies have been our key partners and we are proud to have collaborated on this publication which we hope will have a substantial regional impact.

Noreen M Huni
REPSSI Executive Director
1 November, 2007



National Red Cross Societies in southern Africa have been collaborating with REPSSI on psychological support for children, and memory work in particular, since 2002. Through the Red Cross network of community based volunteers, memory work has spread throughout the region. It is a key tool which can enable parents living with HIV to communicate more closely with their children and plan for the future. As one of our volunteers said – “memory work is a healing process as it removes stress and brings hope and empowerment”.

Françoise Le Goff
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MAINSTREAMING PSYCHOSOCIAL SUPPORT (PSS) FOR PSYCHOSOCIAL WELLBEING

We use the term 'psychosocial' to emphasize the close connection between psychological aspects of our experience (thoughts, emotions and behaviour) and our wider social experience (relationships, environment, traditions and culture). These two aspects are so closely intertwined that the concept of 'psychosocial wellbeing' is considered more useful than narrower concepts such as 'mental health', which focuses only on psychological and emotional aspects.

Mainstreaming PSS means making sure that in every part of the child's life (at home, in the classroom, on the playground, in the street, on the way to school, at the clinic, at the soup kitchen, at the kids' club, etc.) the child feels socially and emotionally supported. Mainstreaming PSS means making sure that this "stream or river" of wellbeing flows widely, strongly and continuously in and around the individual – that we look at every aspect of an individual's life through PSS-tinted lenses. Caring relationships in

everyday life, at home, and in the community, provide individuals with the most suitable and sustainable psychosocial support.

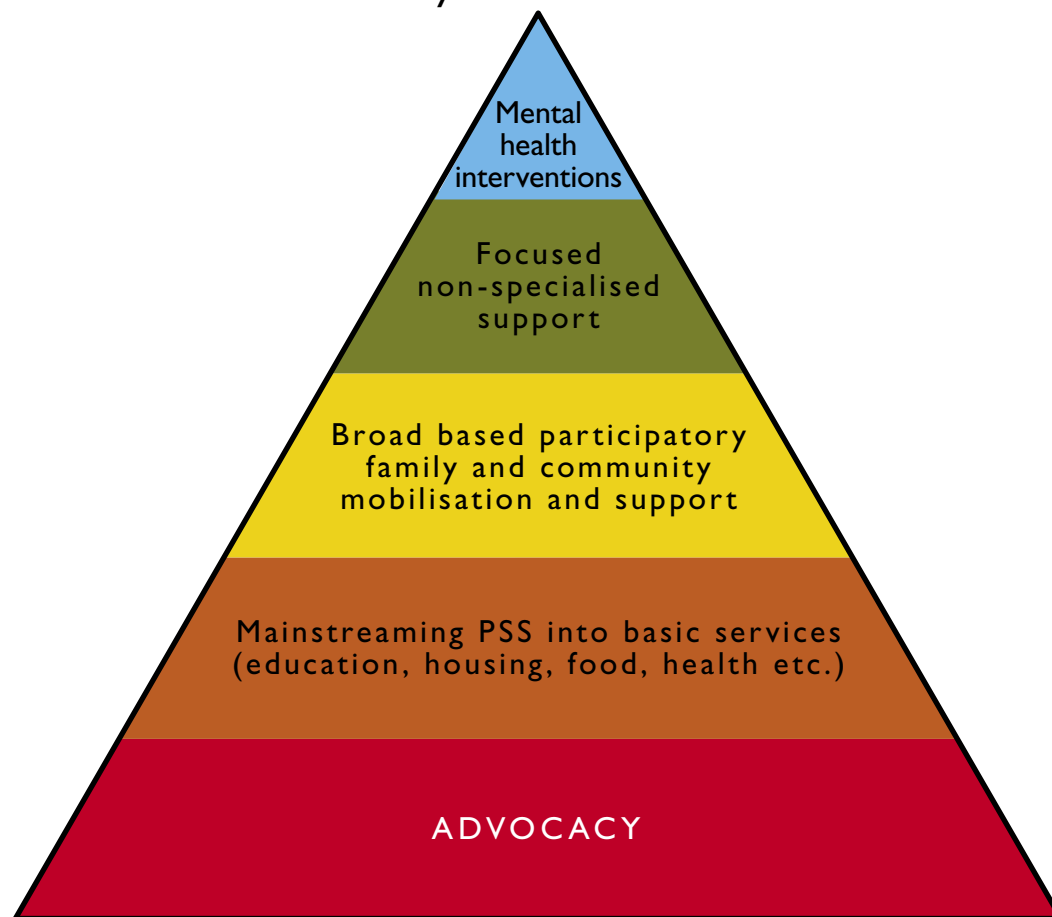
As the following pyramid shows, in terms of wellbeing only a tiny percentage of all individuals need, and have access to, specialised professional, or paraprofessional psychosocial interventions.

Around the development of PSS tools, REPSSI and the national Red Cross Societies try not to fall into the pitfall of undermining everyday psychosocial care and support.

Memory work can be offered as a focused non-specialised intervention in support groups for people living with HIV and AIDS (level 4 in the pyramid), or it can be offered as a broad based participatory family and community support (level 3). Most importantly, memory work is for everyone.

MULTILAYERED, INTEGRATED PSYCHOSOCIAL SUPPORT

few severely affected individuals



all individuals

LEVELS OF PSS:

5. SPECIALISED MENTAL HEALTH

SERVICES: psychiatric, clinical psychological, and specialised traditional healer services, for individuals with clinical mental health diagnoses (potential to benefit only small numbers of the most severely affected individuals at any time)

4. FOCUSED NON-SPECIALIST SUPPORTS

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

3. FAMILY AND COMMUNITY SUPPORT:

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

2. PROVISION OF BASIC SERVICES: food, shelter, education, housing, health etc into which PSS needs to be mainstreamed (potential to affect and benefit millions of individuals at any time)

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

ADAPTED FROM IASC PSYCHOSOCIAL GUIDELINES, 2007

INTRODUCTION

This manual has been produced to help people who want to run memory workshops as part of their work.

Memory work can be defined as creating a “safe space” in which to explore your life story as a form of “self help” or group support. The “safe space” can be a physical space – like a room or the shade under a tree, where people explore and share their life stories just by talking. However, these spaces can also be the space on the pages of a book or on the sides of a box on which you express things about your life by writing or drawing.

Memory work draws on *Narrative Therapy*, which is a way of helping people to find and live out empowering parts of the stories that make up their lives. Often, when we think about our life, we think about what a battle it is. It is also easy to feel like we are losing that battle. In Narrative Therapy and memory work, we try to help people to recognize ways in which they are not only losing and not only victims, but also survivors and winners and heroes in their own special way. Looking for these kinds of stories is called “finding empowering plots”.



Memory boxes and books are used for people to record and tell their own life stories in a new and fresh way. Individuals can narrative their stories in ways that make the teller feel better and stronger, and as hopeful and as proud of their life as they possibly can be. We call this fresh way of telling life stories re-authoring – i.e. retelling old stories that are full mostly with pain. In the retellings, we try and make

sure to note things like courage, survival skills, hopes, important values, how a bad situation can be turned around for good by learning coping mechanisms to help deal with it etc. The boxes can be made out of anything (wood, tin, grass) but cardboard boxes are most often used. The books can be made out of cardboard, string and paper. Memory work also includes other techniques, such as body maps and hero books. These are explained in separate manuals (see Further Reading at the end of this manual).

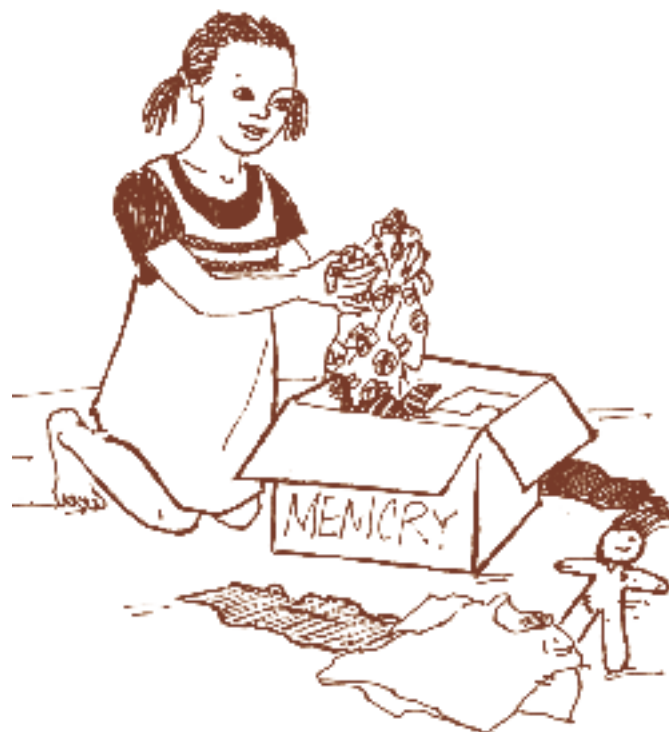
Memory work was begun by a group of HIV positive mothers in Uganda who used memory books and boxes to help them communicate more closely with their children, disclose their positive status to their children, as well as to begin the process of future planning together. However, this is not to say that memory work is only for HIV positive people or that HIV positive people who make boxes and books should mostly write about their HIV status, or that they should only be used to prepare for death. Many of the people we have worked with have used them to fight for, and celebrate, life. Anyone who wants to work creatively with his or her story can do memory work. One person, a parent and child, a whole family or a group can make a memory box or book. This manual will be useful for anyone who runs groups as part of their work.

WHY WE DO MEMORY WORK

The comments below provide a good idea of why we do memory work, and should be read by the facilitator to the participants.

“When you hear the comments that some people have made about memory boxes and books, you will see that people make memory books and boxes for many different reasons. You will also notice that much of this work has been developed with people who are living with HIV and AIDS.”

- “My memory box has helped me a lot. Everything I think I write down on my box. Every time I have a dream, I write it down.”
- “I am talking about my life. I am drawing my mother with me, and my baby, and my child. I make the memory box to disclose my status. I like the memory box because when I write it down then the stress goes away.”
- “I have drawn this fish to show I am alive, just like a fish in the water.”
- “I took my box home to paint and now it will never come back, it is a wardrobe which my child keeps toys and clothes in.”



- “It was good we did not have enough scissors, it made us share and be close.”
- “At first I didn't like it, I thought I was going to die, then I realized it as a good thing, I saw everyone had oomph, we became happy when we were doing it.”
- “I think it can help because when I talk about my status and feelings to family members they silence me by not wanting to hear, when I write I can get it all out.”

- “If I die this box has helped me get ready. I have written my hopes for my children and where they come from. This is not to say I accept that because I have HIV must die. I am a member of TAC the Treatment Action Campaign and I use this box to show people how to fight for life, how to march and how to eat healthy.”

This work is called memory work because the exercising of memory is an important part of this work. But we recognize that this might be a misleading name. In many ways, the work is more about communication than memory, and also more focused on the present and the future than the past.

In the context of HIV and AIDS, this work is designed to open up communication between caregivers and children. This is seen as a good thing in itself, but it also might lead to:

- a) Disclosure of the caregiver's health status and communication around a possible bereavement
- b) Expression and communication of both the caregiver and child's emotions (anxieties, fears, affirmations, feelings of hope and affection, etc)
- c) Communication and planning for the future of the children in which children participate in decisions concerning their future

HOW TO USE THIS MANUAL

- This manual can be used in many different ways. Although the exercises have been presented in a logical sequence, this can be adapted according to the needs and wishes of the group, and specific activities can be chosen while others can be left out.
- The whole manual should take about 30 hours to work through.
- Each session should be about one hour long. This allows time for making art, writing the words, sharing, as well as for individual and group support. You may take longer or shorter, depending on the age, background, and mix of the participants, the size of the group, your way of working etc. It is however highly recommended that the process is not rushed. Perhaps the best time span is to do memory work is for an hour a day, two or three times a week, over two or so months.
- The ideal group size is 6 – 10 people, but it can be done in both smaller and larger groups.
- The facilitator should encourage participants by often praising their drawings and stories, and reminding them that there is no such thing

as a bad artist or a poor drawing. They should never criticize what participants draw, or draw for participants. If they agree, the facilitator or another person can help them if they can't write (see A Note on Literacy below).

- Before the facilitator helps others to make a memory book or box, they should always make their own, so that they have personal experience of the process.
- At the start of each exercise, you will find the **purpose** of the activity, for whom it is **suitable** (i.e. caregivers or children or both), and the **approximate time** you will need for the activity, as well as **materials needed** where relevant.
- The exact words that the facilitator can use to give instructions in a memory workshop are always in “inverted commas” and in italics.
- Many of the activities described below can be done either on the sides of a box, or on the pages of a book, or just by talking. It is important that participants are free to choose how they wish to explore their own life story. Often people prefer to begin with books rather than boxes because they are easier to transport, are more private, and have more surfaces / pages / space than boxes.
- Each memory book or box belongs to the person who made it. They should be free to take these

home with them (for instance if they wish to continue writing and drawing there), or to leave them in a safe place where the group meets (if, for example, they do not have space to store their box at home, or do not want to be questioned about this).

A NOTE ON LITERACY

Because of the overlapping impacts of HIV and poverty, many people in HIV positive support groups might not be able to read and write. Although this remains a challenge, this manual has been designed to make it possible to do memory and life story work with people who fall into this category. The following are some guidelines for this:

- Without causing embarrassment, identify those members of the group who can and those who cannot read and write.
- Explain to those who cannot write, that their stories are really valuable and that if they want to, efforts can be made to pair them up with someone who can write, who can then record their words in writing.
- Also explain that there is no such thing as a good

and bad artist and that if they like, they can try to express themselves by drawing and painting while others are writing. Then if they like they can explain their drawings and paintings and others might record what they say.

- For the purposes of drawing and painting, explain that a symbol is a simple, powerful and clear image that stands for something more general – e.g. a cloud for the rainy season, a flame for heat, etc.

SAFETY NOTES

In the context of HIV and AIDS, poverty and conflict, many people have suffered terribly and are likely to have painful memories. **Memory work has the potential to cause re-traumatization.**

Just by asking people to remember parts of their lives, we might do more harm than good. In some ways, “forgetting” rather than “remembering” may be a healthy response. Having said this, many counselling approaches work with memory and allow people the choice, and offer support for, people to work with their memories (the past), as well as the present and the future.

These are some guidelines for keeping safe while exploring memories:

- What they choose to remember and how deeply they want to dig into these memories must be left up to the participant.
- Memory work is **not suitable** for people who require professional trauma counseling, and should not be used for this purpose. This means that when you screen potential participants, it is important to exclude people who have suffered trauma or severe distress recently. In such cases, there is a risk that the process of drawing and expressing themselves might cause them to re-experience the trauma rather than to heal from it. Group work of any kind is generally not suitable for acutely traumatised people.
- While many of the exercises involve working with adults together with children, it is recommended that adults begin by making their own books, and later share with their children and eventually, if they decide to, disclose to them their HIV status. It is important that the adults are sensitive about when and how to involve the children, and that they remain the guides through this process. When working directly with children, Hero Books (see Further Reading) are more suitable than Memory Books. While under some circumstances it may be appropriate for children to make their own memory books (such as when working with orphans), this should always be done together with adult caregivers.
- Before you begin a memory work process, ensure that you have everyone’s written informed consent. If this is not practical, make sure that everyone at least gives verbal consent. Either way, all participants need to understand that the process is entirely voluntary, and that anyone is free to leave at any point.
- Don’t try to produce examples of powerful, shocking material, which nearly every memory book has the potential to be. Rather keep paying attention to the process, and to safety issues.
- Don’t rush the process. Make sure you are always available as a friendly, supportive co-author, custodian, counsellor and editor.
- Think about, and prepare in advance, how you will react when and if a participant or several participants become distressed or upset as a result of exploring their story and painful feelings. You should feel confident that you have sufficient counselling skills, that you have the support you need to offer one-on-one time for these participants, and that a referral procedure is in place, if need be.
- End every session with a quick evaluation. Ask participants to share what they liked about the session, what they didn’t like, and how things might be improved.

- Be sensitive to the fact that for some people, sharing their stories might feel very threatening and unsafe. Research on the impact of hero books (a form of life story work like memory work) has strongly indicated that many participants prefer not to share the content of their hero books in the group, and that by forcing or putting pressure on these participants to share within the group, you are more likely to do harm than good. Research also shows that many participants like and find it useful to share the content of their books.
- Make it very clear from the outset that it is possible and quite okay to do memory work without sharing and that there is no obligation to share, but for those who want to share, sharing is most welcome. Respect the choice of those who don't want to share, and make sure they aren't excluded from the group. Rather follow the suggested ways to keep them engaged in the role of a 'person on a private journey' within the group. They can play an important role just by being a witness to stories that others want to share.
- Throughout the process, it is important that the facilitator keeps emphasizing that whilst this work involves acknowledging people's painful stories and past, the emphasis is on their new

and positive stories and hope for the future. At the same time, it is important to bear in mind that some participants might really struggle to find any hope or optimism in their lives. The facilitator should be sensitive to real feelings of despair and allow participants to be with these feelings if necessary.

CONFIDENTIALITY AND RESPECT

- As discussed above, people might feel very differently about sharing their work with others. It is important that from the start there are clear rules about confidentiality, which are negotiated together with participants. This will require, but also help create, a safe and trusting relationship between the facilitator and the group from the start.
- Participants should be told that while they are free to discuss their own process and stories with other people in their lives, what they hear from other participants should stay in the room, i.e. they should not discuss personal issues from other participants with anyone after the workshop. The facilitator should similarly assure participants that she/he will not discuss personal issues outside of the workshop.

- It is useful for the facilitator to ask each participant whether they feel worried about sharing personal information or stories, and if so, how worried they feel. This should be recorded by the facilitator so that they can be sensitive to different kinds or degrees of worry during the course of the workshop.
- The facilitator should also discuss with participants the importance of listening respectfully to others people's stories, even when these might hurt or anger or confuse them. It may be useful to think about listening to others as one would hope to be listened to oneself.
- At the onset of making the books when ground rules are being set, it is important that the group discusses what should be done concerning members who break confidentiality. This is in order to assure members that their stories will be "safe" with the group.

FACILITATION SKILLS

I. The Talking Stick and Sharing in the Big Group

The talking stick method was developed by indigenous American people to help people in big groups to listen respectfully, and to make a safe space

in which people could talk about important things without interruption. This is also an important skill, which you will use often in this work. This might be in the last half hour of a group session, or in a session dedicated to sharing or evaluation. Remember that in a support group, it is often good for people to get to hear a wide range of experiences (how different people cope with similar difficulties).

At some point, perhaps after people have worked alone on their books and boxes, and then also shared in pairs, you might want to get people to sit in groups of about 10. Therefore, if the group has about 20 people in it, divide it into 2 groups of 10.

As the facilitator, you will hold the talking stick (any stick-like object will do) and explain to everyone that whoever wants to talk should raise their hand to signal they want the stick so that they can be the talker. This is better than getting everyone to take turns in the order that they are sitting (or the person at the end might be tempted to fall asleep!)

Whoever has the stick should be the only one in the room talking. If it is felt that someone is talking too much, whoever wants to talk should raise a hand, which will signal to the talker to finish off.

It is a good idea to encourage people not just to make their own point, having heard someone else's, but perhaps to respond to what the last speaker said in one way or another. This might be by offering a few words of encouragement, or simply to begin to make their point by saying, "I think I know what you are saying..." and then going on to give their own experience.

Unless a whole session is dedicated to talking and not book or box making, it may be best to encourage people just to share what they are feeling about the work and workshops so far, or something important or pressing in their lives, rather than the content of their books or boxes.

2. Creating a balanced structure

In some ways these workshops are deliberately not very structured. The idea is to try and pass on the basic skills and then allow people to direct the pace and process for themselves. Structure comes in at the level of you the facilitator trying to make sure there is a balance of working alone, sharing in pairs, sharing in the larger circle. Each of these kinds of activities serve important functions. Working individually on books and boxes allows participants to think about their own situation. Working in pairs allows them to hear how one other person is coping. Big group discussions

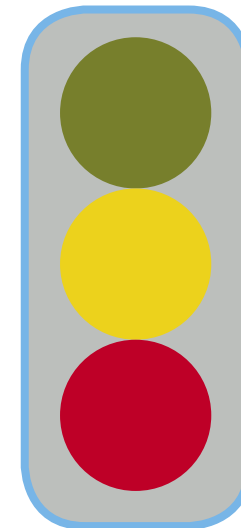
allow them to listen respectfully to a wide range of experiences, and to share their own in this context.

Below is an image of a traffic light that can act as a kind of checklist for you to see that you are leaving enough time or creating a balance between working alone, sharing in small groups and larger circle sharing. Picture all 3 types of activity as a traffic light, where:

Green = people working alone on whatever they want to

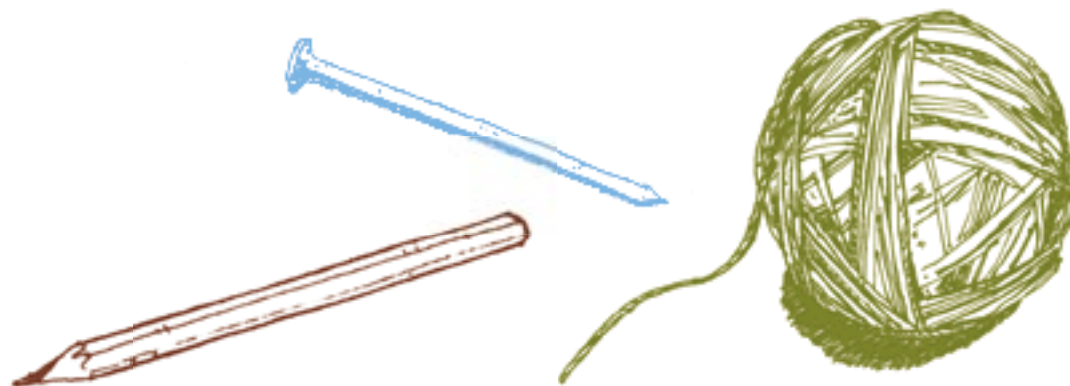
Yellow = people share in pairs

Red = people share in big group



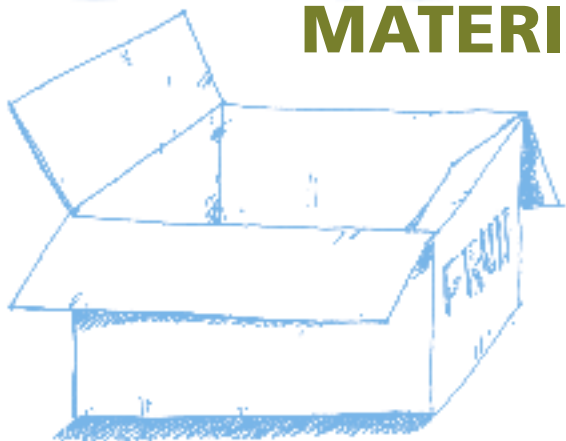
MATERIALS

Before we go on to the actual exercises, here is a complete list of the materials you will find very useful. You can use this list to help you and others prepare for workshops.



	Material	Description	Quantity	Supplier	Tick
1	Boxes and cardboard for book covers	It's good if everyone can bring their own box, it can be any box, a shoe box or a bigger or smaller one, and 2 pieces of cardboard for book covers	1 per person	Refuse bins, shops	
2	Paper	If your organization has plenty of paper that has been printed on one side, bring lots of it	A few reams	Organization	
3	Photocopies of photos	If people can bring photos to the first workshop, they can be quickly photocopied, returned and incorporated into boxes and books	Any	Home	
4	Wax Crayons	Try to find inexpensive ones that have bright colors	1 small box of 10 for every 3 participants	Stationary Shops	
5	Food coloring	A set of red, green, yellow and blue	A set of 4 for every 3 participants	Supermarket	
6	Paint brushes	Very thin small ones that fit into food coloring bottles	4 for every 3 participants	Hardware shop	
7	Pens	Cheapest pens	1 each	Stationary Shops	
8	Scissors	Small	1 for every 3 participants	Stationary Shops	
9	Sponges	Ordinary dish washing sponges with one rough side	5	Supermarket	
10	Nails	10 cm nails	5 for every 3 participants	Hardware shop	
11	Hammers	Cheapest hammers	1 for every 5 participants	Hardware shop	
12	Paper clips	Regular without plastic coating preferably, any will do	1 packet	Stationary Shops	

MATERIALS (continued)



	Material	Description	Quantity	Supplier	Tick
13	String	Not too thick	1 ball per 20 participants	Stationary Shops	
14	Refuse bags		1 roll	Supermarket	
15	Bottles of water to wash paint brushes and sponges				
16	Glue	Any glue that can stick to paper; you can even make it with flour and water; (see instructions for sticking later in manual)	1 liter per 20 participants		
17	Name tags	A self adhesive sticker to write each person's name on	1 per participant	Stationary Shops	
18	Stanley knives	Those blades with a handle - to cut book covers	1 for every 5 participants	Hardware shop	
19	Lots of old newspapers	To work on so that participants don't make a mess			
20	Rulers		1 for every 5 participants	Supermarket	
21	Locally available material for decoration of books	Eg. leaves, flowers, sand, clay, shells, charcoal			

EXERCISE 1: WHAT'S IN A NAME?

Purpose: To get to know one another and explore the meaning of names.

Time needed: 30 minutes

Suitable for: Older children and adults

Instructions:

"In African and in other traditions, some might say you are defined by your names. By your clan name, family name, birth name, the new name you are given at initiation into adulthood, nick names you are given by people who look at you with loving eyes and hearts, and by those who don't look at you with loving eyes and hearts. Right through your life, you might get praise names according to how you live your life. Your names tell the story of your life.

These names are often complex and poetic, and may refer to both good and bad parts of you. For example, "He who Angers Easily but who Resists Fire with Water", or "She who Hears the Sound of Horses Far Away", or "Much Loved Dark Cloud."



Get into pairs and ask each other the following questions:

1. What are your names?
2. Do they have any meanings or stories attached to them that you know about?
3. Has anyone else, perhaps, given you any other names?
4. How do you feel about these names?
5. What is the name you would like to be called and why do you prefer this name?"

EXERCISE 2: THINKING ABOUT WHY?

Purpose: To allow participants to decide if and why they want to do memory work

Time needed: 40 minutes

Suitable for: Older children and adults

A note to the facilitator: It probably seems like a really good idea to be doing all of this. What is perhaps more important is that the group you are working with also thinks it is a good idea. You want them to be motivated to engage in the work and to be able to find their own meaning for making a book and / or a box.

The following questions were designed to give everybody a chance to take ownership of the process, to take a step back and reflect on what they are doing, and to stimulate discussion.

People can answer these questions alone by writing down their responses and then they can discuss them, or the questions can form the basis of a discussion without any writing. These questions can be asked in the beginning of the project, but you might want to ask them again after a few sessions – the answers might change as the process develops.

Instructions (to be read as questions):

- “DO you want to make a book or a box or both?
- WHY? WHY NOT? (For example, you may not have space for a box, or if you cannot write, you might prefer a box to a book).
- WHO is the box/book for?
- How many do you want to make?
- WHERE will you keep your box / book?
- Is the process or the product more important to you?

After thinking about these questions or writing down some responses, perhaps the participants can discuss their responses to these questions in small groups.



EXERCISE 3: MAKING A MEMORY BOX

Purpose: To create another kind of space in and on which to explore your new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 30 minutes

Suitable for: Older children and adults

Materials: There is no limit to the materials you can use to make or decorate your box. The box could be made from wood or grass (like a basket), or tin, plastic or polystyrene; or you can use an existing box or suitcase. We have found that we really love recycling used cardboard boxes.

Note to facilitator: It is important to allow participants to direct their own process here, so that they can make their very own kind of box. Your job is to give encouragement and suggestions if people get stuck.

Instructions:

"In Uganda the box was more or less any container in which to keep the memory book. In South Africa, memory boxes have become important objects in their own right, and the 12 sides (inside and outside) have become like pages of a book.

There are many different ways to make a memory box: you can write, draw, paint or stick things onto the surfaces. You might want to do this immediately, or to plan

it first. This is your box, and it is important that you think about why you are making it (or choosing not to make one), how many you want to make, what you want put in it, who it is for, who you want to make it with, where you want to keep it, etc.

Because there is not a lot of space on your memory box, we are going to work with symbols. A **symbol** is a simple picture, or a word, or a letter, or a shape, that stands for something more complex. For example, a flashing red light means 'Danger!' The number 100 with a red circle around it means 'Speed Limit 100 km/h'. A picture of a dog with a line through it means 'No dogs allowed'. A tattoo of a heart with an arrow going through it refers to a broken heart.



Here are some ideas we took from participants of memory box workshops for the 12 different surfaces inside and outside the box. You can work with these ideas, or make up your own (there are only 8 ideas, so will have to come up with at least 4 new ones!).

- Draw a symbol or design a panel that expresses your **past or where you come from**. You might want to draw your clan symbol or your totem or any symbol that represents where you come from culturally or geographically. You might want to include some photos from your past. Then write a few words that can fit onto the same panel to explain your symbol or panel.
- Draw a symbol or design a panel representing **where you are going to**: a symbol that represents your hopes and dreams for the future. Then write a few words that can fit onto the same panel to explain your symbol or panel.
- Draw a symbol or design a panel representing **you now**. You might want to include a current or recent photo or a portrait that someone paints or draws in the workshop. Then write a few words that can fit onto the same panel to explain your symbol or panel.
- Draw a symbol or panel representing your **windows and plot**. (See exercise 7 and 8)
- Fill up a whole panel with **writing about your memory box**.
- Make a panel for **each of your children or for special people in your life**.

- Write a **slogan or message to the world** about something you believe in or feel strongly about.

You can now begin to plan or to make the surfaces of your own box. You might want to draw or paint directly onto the box using wax crayons and food coloring. Or you might want to stick pictures from magazines or photocopies onto the box. The photocopies can be of original photos, or of your own paintings or drawings, or of old letters or important documents.

If you are wanting to stick things onto your box, you will need to follow these instructions for **decoupage**, which is a technique for glueing paper on to surfaces:

- First you need to prepare your glue. You can use flour and water. Mix enough flour into water until it feels sticky. For some people it is wrong to use food for this kind of purpose. If you use white wood glue (sometimes called cold glue), you can mix one-third glue, two-thirds water.
- Then you take a clean sponge and wipe the back of your page with the glue.
- When it is completely covered with a thin layer of glue, place it onto the box surface.
- Take the sponge again, wet it and wipe the top of the page, squeezing out all the air bubbles and making sure it is stuck nicely to the box.
- Then allow everything to dry before varnishing.

When your whole box is completely covered with writing and drawings, it is good to **varnish** all the surfaces to make them strong and waterproof, as well as to give the box a nice finish. Any clear wood varnish will do, but water-based ones are less messy. The more coats of varnish the better, but make sure to wait until each one dries before adding another."



EXERCISE 4: HOW TO MAKE A MEMORY BOOK

Purpose: To prepare a space to explore life stories.

Time needed: 1 hour

Suitable for: Caregivers and children aged 5 years and up (NB: see Exercise 17, guidelines on the understanding of different age groups of children)

Materials needed: Cardboard for the cover, paper for the pages, a piece of string or wool, a paper clip, and a few long thick nails. A hammer is also useful.

Instructions: (to be read by facilitator while demonstrating the making of a book)

- “Decide on the size of your book (do you want it to fit inside your box?), and cut out a cover from 2 pieces of cardboard.
- Decide how many pages you want and put these in between the covers. 30 pages is a good size if you are using one side of recycled paper. If you are using new paper, 15 pages is enough.
- The next step is bookbinding. Start by squaring up the pages and the cover. If you are using recycled paper, first glue together the two used sides. Then take a nail, and hammer or poke the nail through both covers as well as all the pages. Do this half way down the page, about 2 centimeters from the edge on one side. Leave that nail in and make some more holes in the same way along the spine of the book

until you get near to the edges of the cover.

- Now take the paper clip and bend it into a needle. Then thread the string through the paper clip and the holes, starting with the hole in the centre and working outwards using “blanket stitch” till the book is bound. Tie a knot in the string and remember to leave about 30 cm of string in the middle when you start off if you wish to hang your book up after completion.

Other ideas:

- The ‘demonstration book’ made by the facilitator can then be used as a comments book for participants. At the end of each session, they could record what they liked, what they didn't like, and ideas about how the sessions could be improved. This is a very useful monitoring and evaluation tool.



- When working with children, their book can simply be used to draw in. If a caring adult just asks the child what they have drawn, listens carefully and provides praise and encouragement, this can amount to a powerful form of psychosocial support and communication. Adults and children from the same household can make separate books of their own or share a joint book.

EXERCISE 5: DECORATING THE COVER AND FINDING A TITLE FOR THE FIRST PAGE

Purpose: To help the participant take ownership of the book and to find a title that captures the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 1 hour. This exercise can be done on the same day that people make their books.

Suitable for: Adults and children

Materials needed: Wax crayons, liquid food coloring (that comes in tiny bottles), and a paintbrush.

Instructions:

"After having made a book, people often like to decorate the cover and the first page. This can include drawing or writing, such as your name. Perhaps this is a good time to introduce one of our favorite art techniques.

- *Using the wax crayon, draw or write whatever you want to, making sure to press quite hard.*
- *Paint over your drawing with the food coloring.*
- *See how the wax doesn't allow the food coloring to be absorbed into the paper and the great effect this creates.*
- *Experiment with different colors. Writing with a white crayon and then painting over the words with food coloring works really well.*
- *This technique can be used on other pages and on your box".*



EXERCISE 6: DEDICATION

Purpose: To begin to think about who and what the book is for.

Time needed: 15 minutes

Suitable for: Adults and older children

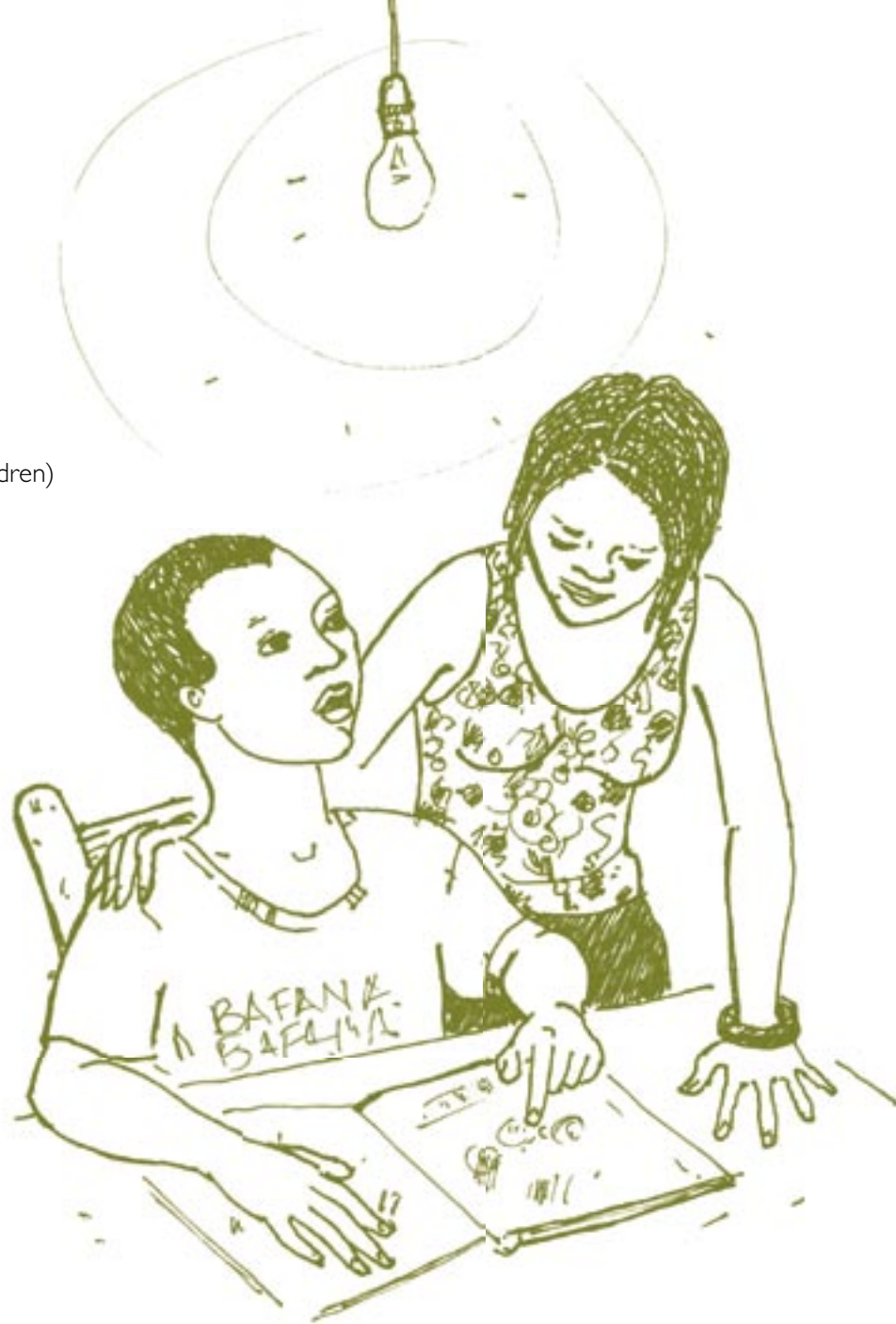
(NB: see Exercise 17, guidelines on the understanding of different age groups of children)

Instructions:

"If you go to a library and open up a few books, you might see something like this:

- This book is dedicated to my mother and my father, may they rest in peace. *Or:*
- This book is dedicated to my children, may they be safe and happy forever. *Or:*
- This book is dedicated to me, myself, I. May we achieve great things.

You might want to dedicate your book to someone".



EXERCISE 7: WINDOWS

Purpose: To explore and re-author your life story to find a new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 1 hour

Suitable for: Older children and adults

Instructions:

"Your life is big but your book or your box is small. You cannot fit your whole story into it. These windows can help you decide which stories and parts of your life you want to you want to draw and write about. Each window is a story about you or a part of your life. Maybe you want to begin with NOW or maybe you want to look at your HISTORY. You can write a heading, or draw a small picture in each of the six windows.

Here is an example of how Busi filled in her windows using drawings of things that stood for other things in her life. We call these drawings symbols:

Busi explained her windows as follows:

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 symbolizes 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 drew 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.

Some people prefer to use words rather than drawings to fill in their windows. If Busi had done this, each her windows might have included the following words:

Window 1: Troubles started 5 yrs old

Window 2: Starting school (excited)

Window 3: Good progress at school

Window 4: Leaving school when family treat me badly; but then earning own school fees and going back to school!

Window 5: Diagnosed with HIV

Window 6: Joining TAC and finding hope

Now, into each window, you can fill in a symbol or a few words, which can then be expanded in a little more detail, as in the examples above."



EXERCISE 8: THE PLOT

Purpose: To find a new story line that captures the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 1 hour

Suitable for: Older children and adults

Instructions:

"The plot is something like a common thread or a story line that runs through all the windows, or that runs through your life story. Often, when we think about our lives, we think about what a battle it is. It is also easy to feel like we are losing that battle or that struggle. In Narrative Therapy and Memory Book/Box work, we try to help people to recognize ways in which they are not only losing and not only victims, but also survivors and winners and heroes in their own special way. Looking for these kinds of stories in their windows is called "finding empowering plots".

A good way to get to the plot in your own life is to begin with the words:

This is a story about and then to add in your own special skills and qualities.

These are examples of how other people have finished the sentence, **This is a story about...:**

- ... a boy who always had hope, and who could see light even when it seemed very dark.
- ... courage and a girl who had lots of it.
- ... me and my family and how we respect one another.
- ... a woman who never likes to give up.
- ... a family who were able to see what got in the way of them loving and supporting each other and who were able to make big changes.
- ... about how I always fight for what I want, like my life right now even though I'm HIV positive

Here are Victoria's windows, as well as the **plot** she identified for herself:



Victoria explained her windows as follows:

For window 1, I drew when I was pregnant in 1995.

For window 2, I drew a coffin box for my first child who passed away in 1996.

For window 3, I drew myself going back to school after that.

For window 4, I drew myself when I was in Cape Town.

For window 5, I drew a radio, I love to listen to Gospel music.

For window 6, I drew me and my child in my house - we are playing outside.

This plot, that runs through her windows and her life story, is **how she never gives up and how she fights for things and values that are important to her.**

Now everyone must fill in their own plots underneath their windows".

EXERCISE 9: THE TELLING

Purpose: To try out, and/or tell for the first time to others the new story line that captures the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 30 minutes

Suitable for: Older children and adults

Instructions:

“Get into partners of two, and invite each other to share your windows and plots, as well as the story about your name. Allow about 7 minutes per person for this initial sharing.

The person who is listening needs to take notes on the following:

- 1. What parts of the story you are listening to touched or moved you the most?*
- 2. What other plot can you think of that runs through this story (different to the person's own plot, but still one that is about courage, survival skills, values and hope?)*
- 3. What you think is a suitable name for the person who is sharing e.g., ‘he or she who never gives up’, or the ‘one with great courage’”.*



EXERCISE 10: THE RETELLING

Purpose: To hear back from the listeners a new story line that captures the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 1 hour

Suitable for: Older children and adults

Instructions:

“Now that everyone in your group has had a chance to tell their stories, the ‘listeners’ can encourage the ‘tellers’ by re-telling their story back to them in an empowering way.

- To begin with, each ‘listener’ should use the words that they have written down to create a new story out of the one they have listened to in exercise 9. They should re-tell this story to the original ‘teller’ of the story in turns.*
- During this retelling, make sure you listen to, and try your best to include, a story that has hope, and that highlights the storyteller’s positive qualities.*
- When you do the retelling, you can imagine you have just a few minutes to convince the judge of the Worldwide Hero of the Year Award why this person is an amazing hero and why they deserve the award. Don’t forget to say what you think is a “good” name for this person”.*
- The listener should write the “good” names they have come up with in the teller’s memory book as he/she will want to remember these encouraging names in future*



EXERCISE 11: ENCOURAGEMENT TO GET YOUR STORY GOING

Purpose: To find word or a few words to get you going in telling your new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 30 minutes

Suitable for: Older children and adults

Note to facilitator: Some groups have found the “A day in my life” prompt particularly useful, and you may want to spend more time elaborating this one.

Instructions:

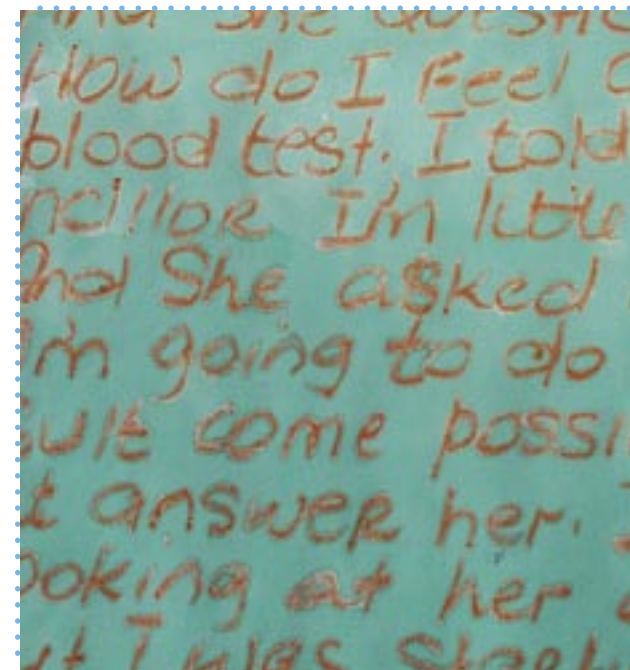
“A prompt is a word or a few words to get you going when you begin to write or tell or draw your story.

Below is a list of prompts we have found to be useful. Some of them are designed with children in mind. For some you might want to write a few words, and for others a few pages. You may prefer to draw instead of write.

I want to say... (something that is important to me)
A day in my life....

Our family came from...
Our family traditions and values were...
You first walked and talked when you were...
Here is the most important advice I would like you remember when you are older...
My hopes for you are...
Your grandparents' names were...
Childhood...
School days...
Finding out I'm HIV positive...

Here are some responses that people have made to the prompts, as well as some comments about the prompts.



A day in my life: This morning I woke up at 5, I brushed my teeth and fetched my friend from the hospital at Site B. After that I took her home, she was having a baby, and after that I helped her to bath the child and make her something to eat. Then I make myself ready to come to do memory box work (Victoria, 2003).

Our family came from Eastern Cape, a place called Qoboqobo. I was staying with my mother and father, and my mother's mother. With grandmother we used to go to the bush to collect wood (Mandisa, 2003).



Our family traditions and values were: In my family, the traditions are we cut the fingers. We are the White People, the White Family. This does not mean we are Europeans, we put white on our faces because we are the witch doctors, but I don't follow all of that. I follow cut the finger because I was young when my father cut my finger. When I was 15, they slaughtered a goat for



me, they say they want me to get better. I was wetting the bed when I was sleeping. After that I didn't do that anymore. I believe some of these traditions. I believe that when you get sick in your body and you make umqombothi and you talk to izinyanya (the old people who passed away long time ago), you feel better. If you know their names, you can call those, or you can just

call them grandfather and grandmother, Baba and Gogo (Victoria, 2003).

You first walked and talked when you were 9 months, but your talking was not perfect. You say Mama ndifuna I toilet, Mummy I want the toilet. Your favorite food is umvubo, mielie meal with sour milk.

Here is the most important advice I would like you remember when you are older: I am HIV positive but I took AZT when I was pregnant with you so you are not positive. You are negative. I want you to always use a condom when you are older if you have a girlfriend. I don't want you to be positive like me. My hopes are for you to be finished school. If I am alive, I want to see you as a lawyer or a teacher. (Nomonde, 2003, writing to her son).

My hopes for you are that you to grow up nice... I hope you become a priest, you like Church so much. I am HIV but I feel positive in my mind. I'm not thinking about dying. My future, my everything. In my heart, I feel strong. I am HIV, but when I write in my memory book, I feel happy. We are laughing every day in this group. My book is something special to me. I'm thinking about you and I am not giving up (Maria, 2003, writing to her son).

Now you can write or draw your own responses to some of the prompts".

EXERCISE 12: ZOOMING A WINDOW

Purpose: To explore in more detail and in private, the 'flesh on the bones of the skeleton' of the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, important values and hope).

Time needed: 30 minutes

Suitable for: Older children and adults

Instructions:

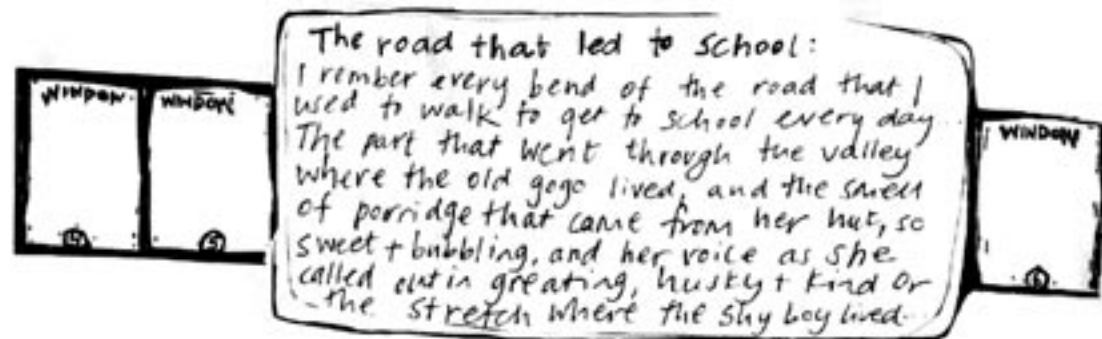
"Remember when you sketched out your story across six windows? There was very little space in each window so you just drew a symbol or wrote a few words in each one.

To ZOOM means to make something that is small into something that is BIG. ZOOMING a window therefore means expanding that symbol or key word into a larger story. Whether you do it on one of the panels on your box or on a nice big clean page in your book is up to you. 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. Remember to add detail in the form of voices, sounds, smells, textures, tastes, colour, etc. Also remember to include your survival qualities that make you into a hero in your own life story.

Here is an example of the beginning of a zoomed window".



ZOOMING A WINDOW



EXERCISE 13: REFLECTING THE OTHER THROUGH A PORTRAIT-POEM

Purpose: To reflect how we can act as mirrors for one another focusing on the positive aspects and thereby empowering each other

Time needed: 30 minutes

Suitable for: Older children and adults

Notes to facilitator:

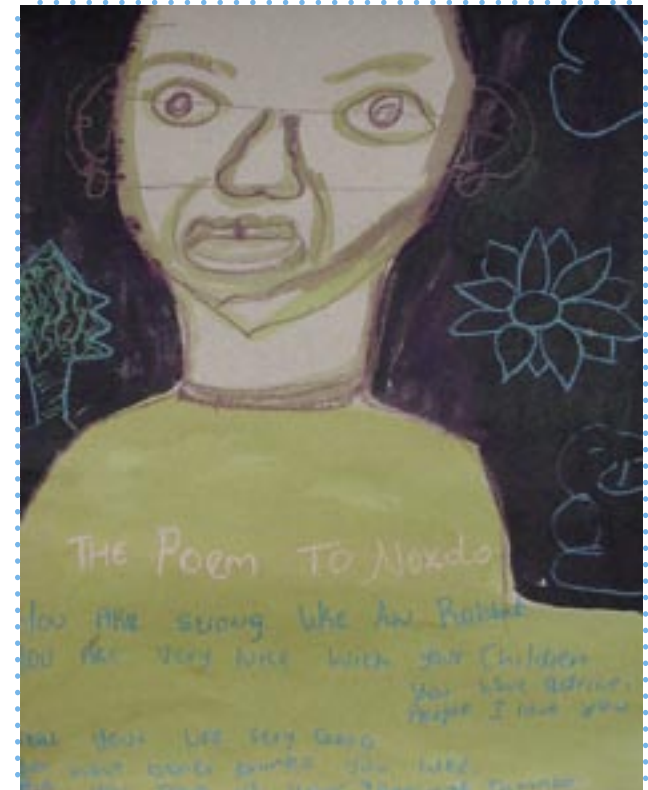
- It is best to do this exercise once people have been given enough time to work on their books or their boxes.
- The best way to introduce this exercise is for you and your co-facilitator, or you and a volunteer from the group, to quickly role-play the exercise in one or other form in front of the whole group.
- This exercise can also be done in groups of three, which is a bit more complicated, but allows for interesting interactions and often richer completed portrait-poems.

Instructions:

*"A **reflection** is what you see when you look in a mirror. We can act as mirrors for each other. Because we often hold negative self-images of ourselves, reflections that are offered in the spirit of kindness and sincerity can often be powerfully healing and supportive."*

*A **portrait-poem** is a picture of your face, drawn by your partner, plus a message to you that they have written, telling you why they see you as a hero."*

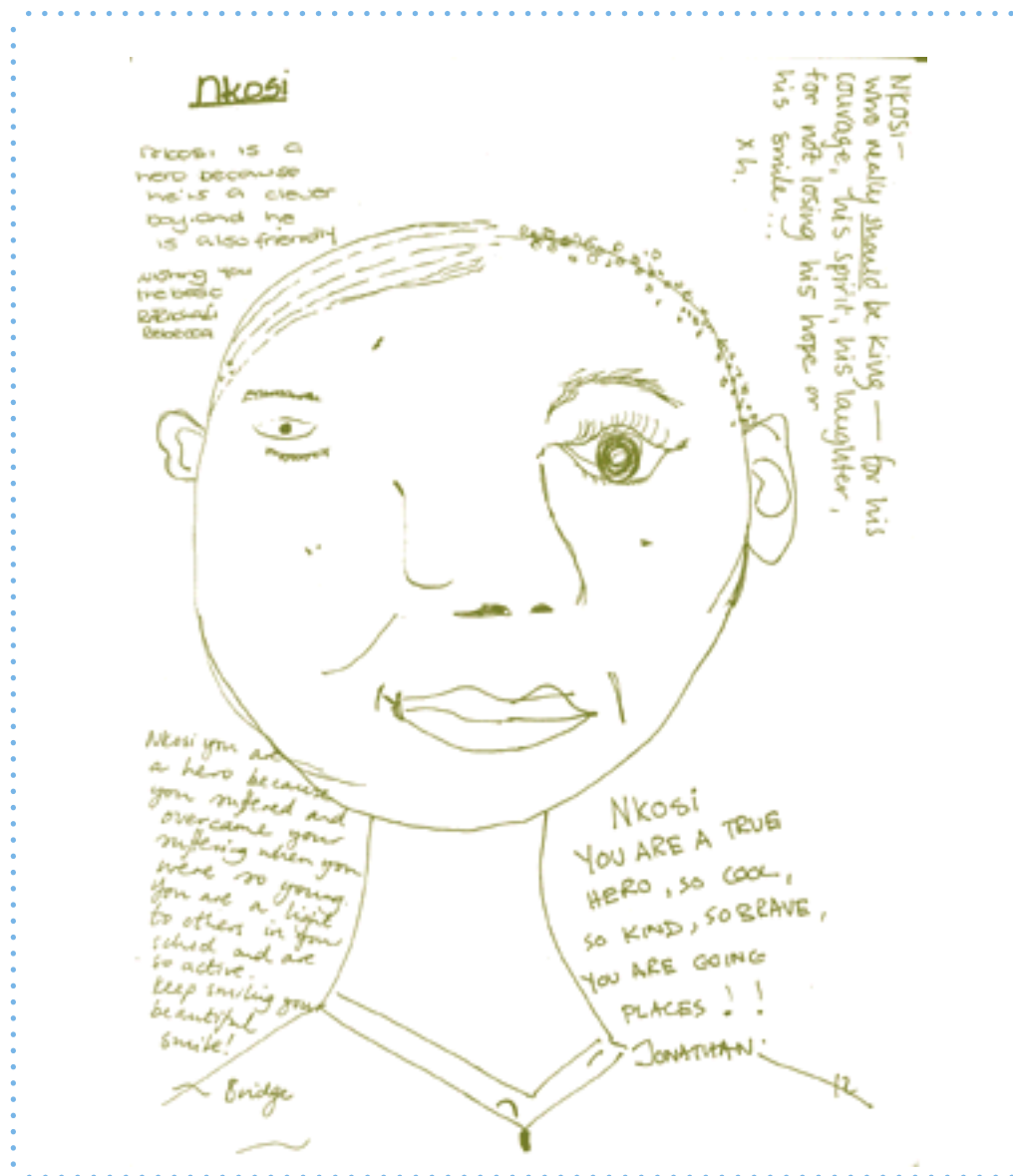
- "We want to find out how you feel when you share your book or box or a part of your book or box with a partner. It's fine if you don't want to share in this way – you can still be part of this activity."
- If you do want to share, please find just one bit of your box or book that you want your partner to see.



- Get into pairs , and take turns (up to 5 minutes each) to show this bit to the other.
- Once you have both shared, each write your name on the top of a blank page of your memory book and swap books with your partner.
- Take a look at your partner, and take a minute to draw their face.
- Remember what they shared with you, and anything else you know about them. Now write on the side of the picture (if you cannot write have someone else write for you) what you most like about them, and why you think they are a hero. This can be a word, a phrase, or a short message. Sign your name under your message.
- You can also include a blessing starting with the words "**May you...**" For example, 'May you live long and grow fat and healthy', 'May you fulfill all your dreams', or 'May you win the lotto'.
- Then swap books again so you have your own in front of you.

One participant said about "The exercise showed me that hard times never kill. When other people encouraged me I felt that my burdens were made lighter and I felt encouraged to move on because the future seems bright."

Here is an example of a portrait-poem:



EXERCISE 14: FAMILY TREES

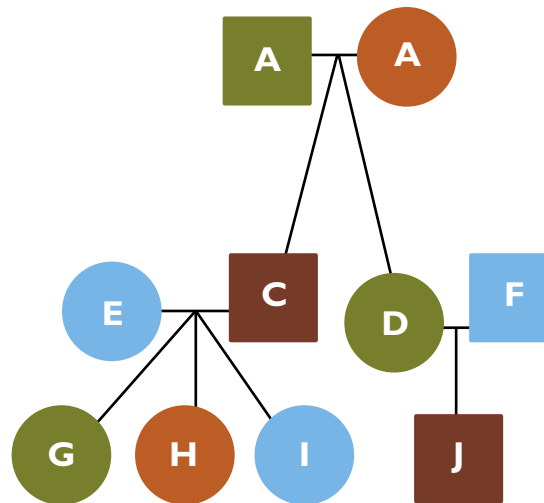
Purpose: To link the family history or your own history or whatever you know or imagine it to be to the new story line of the new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope).

Time needed: 1 hour

Suitable for: Older children and adults

Instructions:

"A family tree is a list of all the members of a family showing how they are related to each other. You can use a □ for a man and a ○ for a woman and a line joining them to show they had a relationship. Here is an example where grandfather A married grandmother B, and they had 2 children C and D. Then C married E and D married F. C and E had 3 daughters, G, H and I. D and F had one son J.

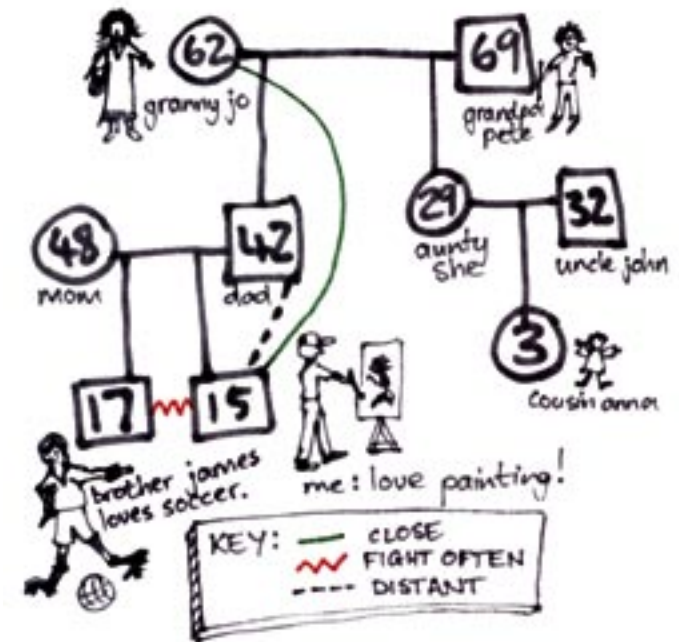


- Now you can make your own family trees starting with a basic outline like this.
- Then you can fill in the names of all the people in your family, as well as their dates of birth and death, and their ages.
- You can also make small drawings of each family member if you like.
- You might want to show with different coloured lines

what the relationship between two people is like. For example, you could draw a red dotted line between two sisters who fight a lot, or a green straight line between a mother and son who are very close.

- You can then add in any other information about your family.

Here is an example that includes some of the above ideas:

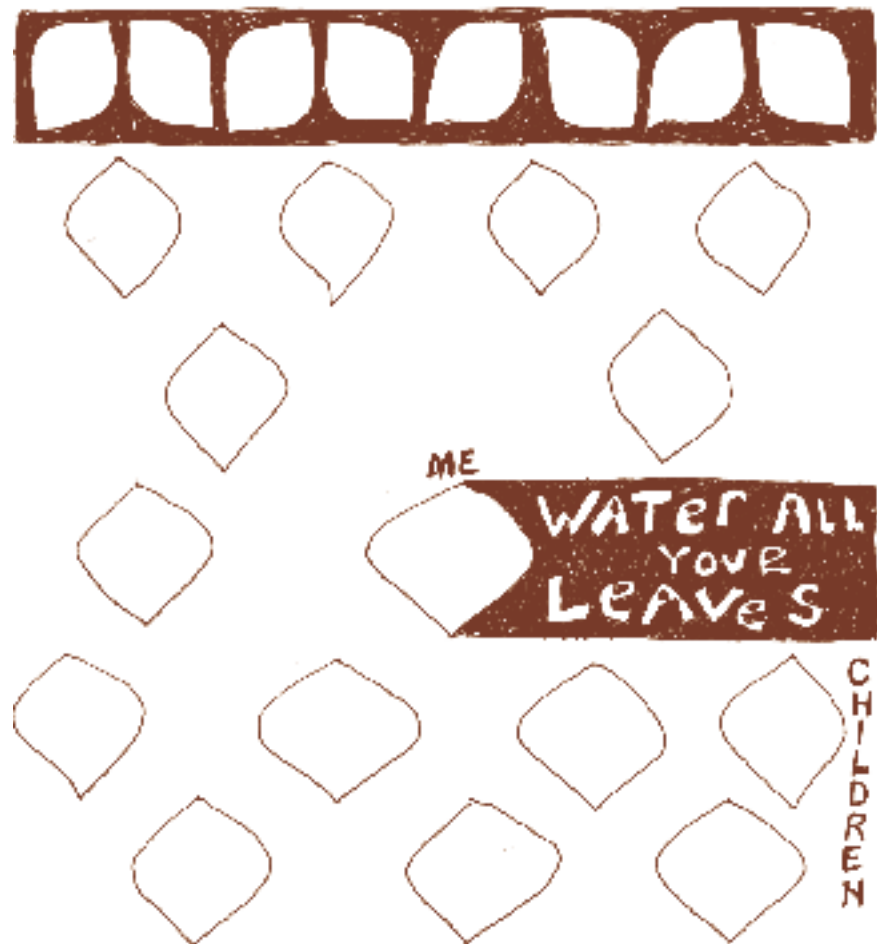


Other ideas: There are more creative ways to do family trees, and you are encouraged to come up with your own. One idea is to make a chest of drawers out of stuck together matchboxes. Each match box can then open up like a drawer, into which some basic information about each family member can be stored. You can also make a mobile which is like a real tree with branches and string.

Below is a diagram that you can use to document your history and the relationships that are important to you. It is called **‘Water all your leaves’**, but it can also be thought of as ‘Water all your Roots’!

- Begin by filling in your own name in the large leaf at the bottom.
- Above that, there is space for your parents’ names and above that for their parents.
- Space (but not leaves) have been left at the very top and bottom for great grandparents and children.
- Like the windows exercise, you can begin to write stories about them, which you might want to complete in more detail on a new page in your memory book.
- Remember to try and detail the history of your new and fresh and story and find examples of hope, courage, pride etc in your own history.
- You can also ‘zoom an ancestor’ – i.e. take more time and space to provide more detail about a family

member on a new page”. Different people have felt differently about doing this part of the exercise – some remembered new things about their relatives, and others felt pain to realize how little they knew.



EXERCISE 15: TALKING ABOUT HIV – DISCLOSURE I

Purpose: This section of the manual includes exercises that are designed to stimulate discussion about disclosure of HIV status within HIV positive support groups. By definition, members of these groups are aware of each other's HIV status but they might want to explore possible disclosure to others including children and spouses. These exercises are also designed to help improve communication between caregivers and children. But before children are invited to participate at all, we recommend a series of sessions in which adults can prepare for the journey ahead.

Time needed: 30 minutes

Suitable for: Teenagers and adults

Instructions:

*Memory Boxes and Memory Books can be made for many reasons. In Uganda, where memory work first took place in Africa, HIV positive women began making boxes with their children as a way to **begin to talk about their HIV status**. They recognized that disclosing one's HIV status, particularly to one's own child, is a very difficult thing for to do.*

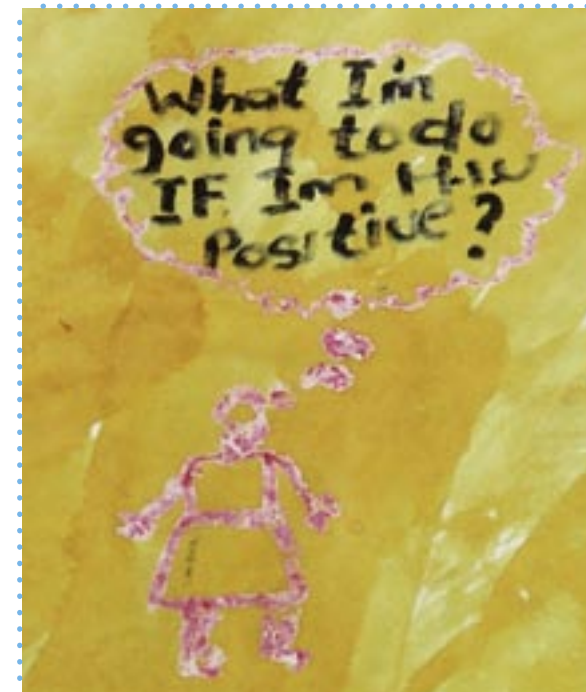
*We think it is important to think about disclosure in a focused way. To do this, we will now **practice***

disclosing. This will also help us get to know different group member's ideas about disclosure.

- Start by each dividing a page into 4 parts, and filling in a table like the example below.
- You must choose the name of a real person for each block, and then fill in how you might disclose to that person.
- After you have completed this, share the contents of your table with other people in your group, and discuss.



An adult who its easier to disclose to:	A child who its easier to disclose to:
<p>Name of adult: Simon Age of adult: 42 Relationship to you: friend "Simon, I have something to tell you..."</p>	<p>Name of child: Mary Age of child: 6 Relationship to you: daughter Exact words you might or did use to disclose: "Mary, have you heard about HIV? Well..." Or: "Mary, now-days people are opening up about HIV, and..."</p>
An adult who its more difficult to disclose to:	A child who its more difficult to disclose to:
<p>Name of adult: Sarah Age of adult: 23 Relationship to you: Boss Exact words you might or did use to disclose: "Excuse me, Sarah...I have something I would like to discuss with you..." Or: "Hello Sarah, I wish to find out whether our organization has an HIV and AIDS policy..."</p>	<p>Name of child: Benny Age of child: 4 Relationship to you: son Exact words you might or did use to disclose: "Benny, umm... I have a long illness I need to live with but you don't have to worry, I have medicines that can keep me well."</p>



Note to facilitator: The following points can be used to guide the group discussion. You do not have to agree with all the points.

1. Disclosure is a process and not an event particularly when dealing with younger children they will need more preparation time.
2. You can't just say "I'm HIV positive, full stop." The disclosure process should be ongoing and should rest on good general communication around a range of issues.

3. Disclosure does not automatically mean you tell everyone about your HIV status.
4. The person who is thinking about disclosing might be worried about confidentiality and might be worried that the child might tell others who she is not ready to share this kind of information with. Does this mean one should not disclose to children?
5. For young children, a lot can be said without using the words HIV and AIDS. HIV and AIDS can be very scary words. You might explain to them in ways that

are appropriate to the child's age that make HIV and AIDS sound less scary, for example, "a long illness I need to live with".

6. Life Story Work or memory work can be used to open up communication; they can be used to begin a long term – ongoing – probably difficult – conversation about HIV, using carefully chosen language. Can you see how this kind of work might help you with disclosure?

EXERCISE 16: TALKING ABOUT HIV – STAGES OF ILLNESS AND ARVS

Purpose: To strengthen participant's understanding that their feelings about disclosure might have a lot to do with their understanding of HIV.

Time needed: 30 minutes

Suitable for: Teenagers and adults

Note to facilitator: If this discussion is taking place in a support group, where participants have all disclosed, the following exercises can be done in pairs. If not, discussion should take place in the big group to protect those who do not wish their status to be known.

Instructions:

*"What are your feelings about disclosure? We believe that these feelings might be strongly influenced by your feelings about HIV more generally, and in particular whether you feel like the **passenger** or the **driver** in relation to HIV. A passenger is just taken along for the ride. A driver has more control about where he or she is going.*

On ARVs, patients generally reverse the direction of the illness. Instead of getting sicker and sicker, by taking their ARVs regularly and properly, they get better and better. Even people who are living with HIV who are not on

ARVs are not powerless in relation to HIV.

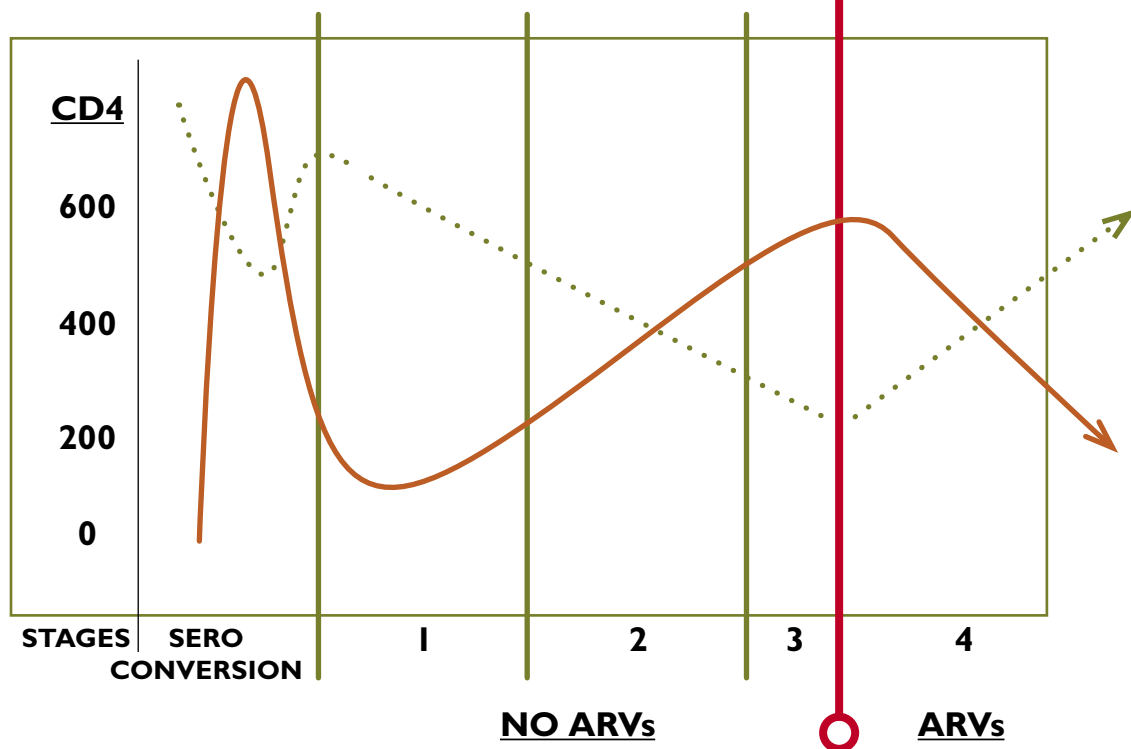
Remember a passenger has no control over where he or she is going. He or she just gets taken along for the ride. A driver can steer the vehicle, change the speed and even reverse. Can you change the direction of where HIV is taking you? Can you control the speed? Can you reverse?"

- *Have a short discussion about this in the big group (or in pairs, if working in a support group).*
- *Then have a look at the graph below, which shows the way HIV develops into AIDS in most people **if they don't get any treatment**. These are the **four stages of HIV illness** identified by the World Health Organization*
- **SERO CONVERSION:** Mild flu-like symptoms
- **STAGE I:** No symptoms of any illness. This stage

can last from 6-11 years. (CD4 cell count +500).

- **STAGE 2:** Mild disease, with first signs of immune system weakening, and minor complications such as weight loss, or frequent coughs and colds. (CD4 cell count –500).
- **STAGE 3:** Moderate disease, for example chronic diarrhea, lasting fevers, thrush, and TB. (CD 4 cell count – 350).
- **STAGE 4:** Severe disease, which can include more than 30 different conditions such as Cryptococcal Meningitis, Pneumonia, Kaposi's Sarcoma. These diseases are life threatening, and at this stage the illness is called Acquired Immune Deficiency Syndrome, or AIDS. (CD4 cell count – 200). Once ARV treatment begins at this stage, we see a rapid reversal of symptoms and an increase in CD4 cell count and a decrease in viral load.
- *The only way you can accurately know where you are*

Stages of HIV/AIDS



..... **CD4 count**
 ——— **Viral load**

SERO CONVERSION: MILD FLU-LIKE SYMPTOMS

on the graph is by consulting your doctor and finding out your CD4 cell count.

- However, even without knowing your CD4 cell count, you probably know if you are HIV well or HIV ill
- The important thing to remember is that with proper advice and help as well as your own efforts, you do have some control over your health.
- People have been known to go backwards from a more unwell stage to a healthier stage even without ARVs by practicing positive living e.g. regular CD4 cell counts, use of condoms to avoid re-infection, avoid stress, exercise, eat locally available nutritious food.
- With ARVs people have managed to raise their CD4 cell count from as low as 10, to normal levels, and to the point that the HI Virus is undetectable in their bodies.
- Most people do not know when they became infected with HIV, but some people know how long it has been since they first tested for HIV.
- It is important to encourage people to go for VCT but they must be assured of confidentiality

Discuss in the big group (or in pairs if working in a support group):

- Where you think you are on the curve
- Whether you feel like the passenger or the driver. Perhaps you and HIV are co-drivers?
- What can you do to stay or become HIV well?

EXERCISE 17: TALKING ABOUT HIV – DISCLOSURE II (PROS AND CONS)

Purpose: To explore possible reasons for and against disclosure.

Time needed: 30 minutes

Suitable for: Teenagers and adults

Instructions:

“Sometimes when we face a difficult decision it is good to make lists comparing the different choices. In the following tables, you will see lists of things that others have said about why they should or shouldn’t disclose their HIV status. These may help you start to ask these questions for yourself. The first table is about disclosure to children, and the second one about disclosure to adults”:

- Looking at the first table below, decide if you agree or disagree with each reason
- Tick the ones that you agree with, and cross out those that you don’t
- Add in some of your own reasons in the blank parts of the table
- Then look at the second table, and fill in your own reasons in the blank spaces
- When you are finished, discuss in small groups what you wrote and feel

Table 1

Why i should disclose to my children	Why it’s difficult for me to disclose to my children
I would rather the child hears it from me I can decide what to say	I have not told others and I’m worried that my child will tell others
The child may need to prepare for tasks ahead and protect themselves from becoming infected (sickness, painful procedures, discrimination and death)	I do not want to worry my child
I want my children to know from me the modes of transmission of HIV so that they do not contract HIV as I did	I do not know the impact this would have on the child
We as adults need to help children talk about fears and feelings	I think I should begin to talk about this but I just avoid it – it is very difficult
Maybe the child has already picked up some signals or someone else has said something, and I think I can reassure him or her	I think it will harm the child
I often feel guilty but I need to keep telling myself that this thing is not my fault	I think my child might reject me
Research has shown that disclosure to children helps both parents and children psychologically	
My children could help me with adherence to my medicines if they know about why I need to take these	

Table 2

Why i should disclose to adults in my life	Why it's difficult for me to disclose to adults in my life
I feel I have nothing to be ashamed of	I feel it is my business and a private issue.
I need treatment support from others, and it is more difficult to keep taking my ARVs in public when I have not disclosed	Disclosure might break confidentiality and may lead to discrimination which would stress me
Disclosing will help me access psychosocial support	I would be afraid of people's reaction towards me. For example, I would be afraid of losing my job or that my partner would leave me.
By disclosing, I can share knowledge on issues regarding HIV and AIDS and dispel myths and misconceptions	
My disclosure may encourage those not tested to go for Voluntary Counseling and Testing	

SOME MORE INPUT AROUND DISCLOSURE TO CHILDREN

1. When is the right time to disclose to my children?

- Each family must decide this according to their particular needs and circumstances.
- Look for clues from your children that might suggest signs of distress and therefore that it is time to disclose to them, such as behavior changes (eg. fights, clinging).
- If they are asking direct questions, this is a good indication that they are ready or needing to know more.
- You can sometimes check out a child's readiness

by asking them indirect questions, such as "I haven't been feeling well lately, have you noticed?", and their answers can guide you.

- There is no "rule" about age: always adapt the information to the child's personality, maturity and age (see below).

2. Guidelines about how to disclose appropriately to children of different ages

2-4 year olds

- These children do not understand difficult ideas or adult sexual behaviour.
- They are learning about the world through play,

so you can use play to explain things to them.

- Parents should start creating a climate in which children feel free to ask questions.
- With all the age groups always remember to use age appropriate language

5 - 8 year olds

- Children at this age are able to understand more complicated issues.
- They understand the world through everyday life experiences, and you can use real examples from their lives when talking to them.

9 - 12 year olds

- They are able to understand more complicated information and they need preparation for things that will happen to them.
- They need to know practical sex information.

13 - 19 year olds

- They can be told the whole truth of their situation.

3. Points to consider in disclosing to children:

- Many children believe that another person's sickness is the child's fault – as a result of something they said or did. They need reassurance that the parent's illness is not a punishment
- They need to be told you will do everything within your means to help them
- Children need to hear that the virus is not contagious

- Check out their level of understanding in relation to HIV and AIDS
- Try not to alarm or frighten them unnecessarily
- Be as simple, clear and honest as you can.
- Disclosure is not just one conversation – it is a process
- You might want to discuss possible scenarios with people you trust, that may come up before you tell your child

Now get into small groups, and discuss:

- What are the most important things that you want your children to know? *For example, you might want your children to know that you are ill but that you love them and that you will do everything you can to make sure that they are safe and well looked after. Depending on the age of the child, give them information on HIV and AIDS, modes of transmission, treatment, how to avoid risky behaviour and how to handle peer pressure.*

After this discussion, write down exactly what you might say to your children. If you have more than one child, think about each one separately.

Then go back to what you wrote in the squares earlier on, and decide if there is anything you would like to add or change after all this input and sharing. You can write down your new or revised messages below:

Now share these messages in small groups, and allow time for constructive criticism and support. Decide if there is anything you want to add or change after this.

Finally, discuss this whole process all in the larger group.

An adult who its easier to disclose to:	A child who its easier to disclose to:
Name of adult: Age of adult: Relationship to you:	Name of child: Age of child: Relationship to you:
Exact words you would use to disclose:	Exact words you would use to disclose:
An adult who its more difficult to disclose to:	A child who its more difficult to disclose to:
Name of adult: Age of adult: Relationship to you:	Name of child: Age of child: Relationship to you:
Exact words you would use to disclose:	Exact words you would use to disclose:

EXERCISE 18: PLANNING FOR THE FUTURE

Purpose: To explore and communicate a sense of future with the child.

Time needed: 30 minutes

Suitable for: Children and adults

Instructions:

"Complete the following sentences, in which you as caregiver, and your child, take turns speaking about the future:

- **Caregiver: When I think about the future, I believe I can...** (For example, Complete my studies, Keep showing I love you even if I get very sick, Keep fighting for life and to be with you, Get access to treatment and live till I am 100)
- **Caregiver to child: When I think about the future, I believe you can...** (For example, Finish your education and become a great person, Keep looking after your siblings, etc...)
- **Child: When I think about the future, I believe I can...** (For example, Be strong and independent)
- **Child to caregiver: When I think about the future, I believe you can...** (For example, Grow old in peace and in health)
- **Child: When I think about the future, I believe we can...** (For example, Keep being close, Go to Namibia together on holiday and see the lions in the desert....)
- **Caregiver: When I think about the future, I believe we can...** (For example, Learn to live together with all the challenges that might face us)"

EXERCISE 19: MAKING A WILL

Purpose: To allow your wishes to be known after you die

Time needed: 1 hour

Suitable for: Adults

Note to facilitators: The laws concerning wills vary from country to country, so please check that the guidelines below meet the legal requirements in your country.

Instructions:

“Written wills might or might not be part of your culture. Remember culture is always changing, and it is people who change it. You will decide if you want a will or not. Beatrice Were from NACWOLA, the National Association of Women living with HIV and AIDS in Uganda, once wrote:

One of the ways some positive women are dealing with the possibility of death is by concentrating on practical plans. We’ve sorted out our wills, we’ve planned our own funeral and where necessary the funeral of our partner. We’ve made arrangements for our children to be looked after by relatives or friends.

Most people will tell you that it is a good idea for everyone, no matter how healthy or sick or old or young,

to have a Will. A Will is a written document, which makes clear what you wish to happen after your death.

A Will can do the following:

- *Ensure that your property, land and valuables are passed on to the people that you want to receive them*
- *Make clear who will look after your property, land or valuables until your children are old enough to do so themselves*
- *Make clear who will look after your children in future*
- *Appoint a guardian to look after your children*

In order for a Will to be legal you need to:

- *Write the date on which you wrote the Will on every page*
- *Sign or make your mark on every page in the presence of a witness*
- *The witness must also sign the Will on every page, in your presence*
- *Appoint an executor who is the person who will make sure that your intentions and wishes are carried out after you die*

- *The witness must be a person who is not mentioned in the Will*
- *The Will must be written when you are in sound mind and you are not forced to write the Will by anyone else*

Appointing a guardian for your children

- *It is important for all of us to choose a guardian for our children when we think about dying and when we think about the future of our children without us.*
- *Talk to the person you have chosen and make sure that they are willing to look after your children.*
- *Wherever possible, the child should participate in discussions and decisions about his/her future*
- *Consider starting the process of handing over guardianship of the children while you are still alive so that the children and the new guardian can get used to each other - arrange visits between the guardian and the children*
- *How you explain to your children about the future and appointing a guardian, will depend on you and your situation*

Below you can see a format of a Sample Will

1. This is the last Will of (put your name and place of residence here)

2. I want (put the name of the Executor - the person who carries out your wishes here and his/her place of residence) **to be the Executor of this Will.**

3.

I leave:

(Put the property/land/ or valuables here)

.....
.....

To:

(Put the names of the people you wish to receive them after your death here)

.....
.....

3. I appoint (put the name and address of the person who you want to look after your children here) **as the guardian for my children.**

Signed at Place where you have made the will) **on** (day, month, year)

..... (Sign here)

Witness

Name

Signature

Address (physical address)

Date

Place

In addition to making a will, it might be useful to store copies or originals of certain documents like birth certificates, ID books, title deeds, etc. A memory box, especially one that locks, is a good place for these. An even safer place is a community leader's or a lawyer's office.

EXERCISE 20: THE SPIRAL

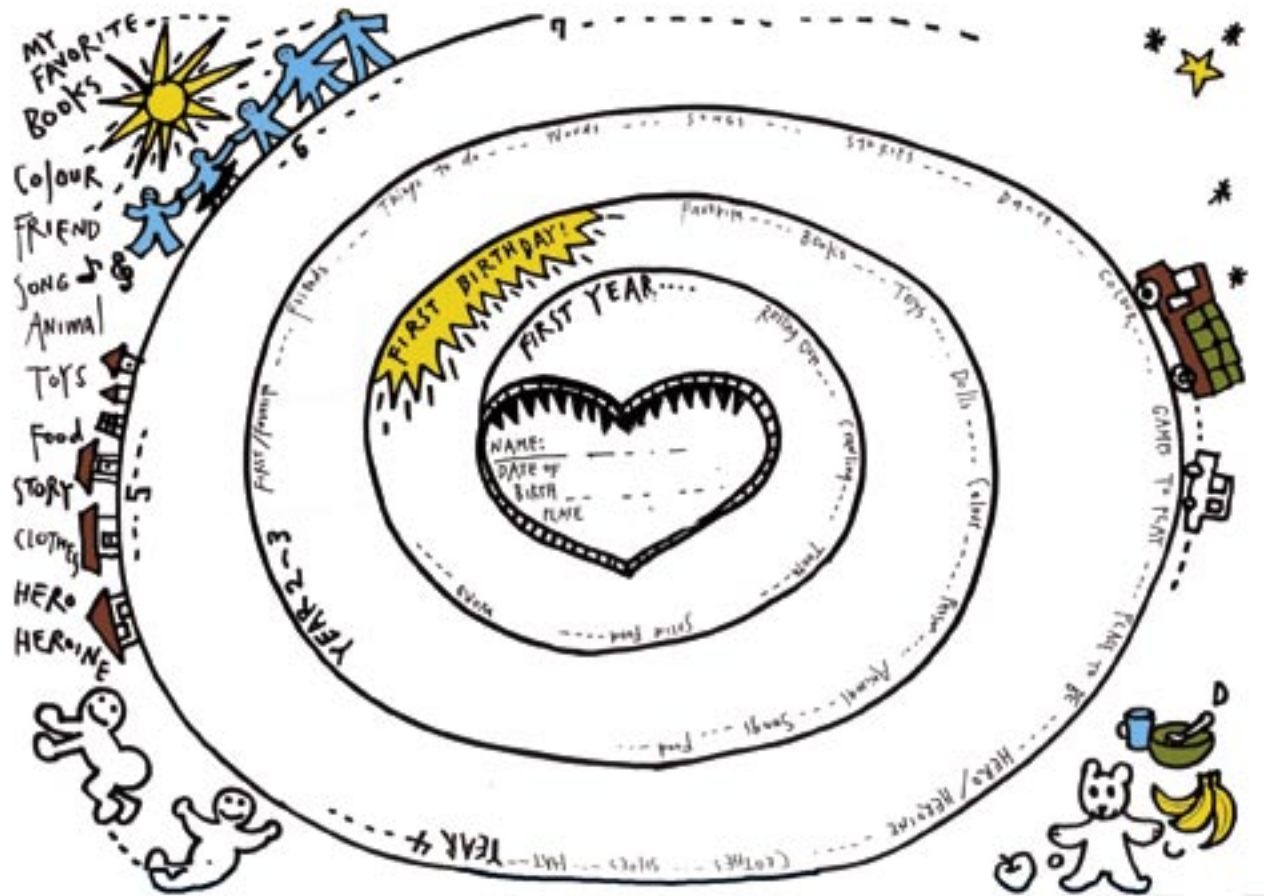
Purpose: To bring the child right into the conversation and to help the child remember his or her early years.

Time needed: 30 minutes

Suitable for: children age 3 and up, with caregivers

Instructions:

The parent or guardian should copy the spiral diagram into their memory book and the fill in the diagram while the child listens, talks back and colours in the pictures on the diagram.



GUIDELINES FOR ILL OR AGEING CAREGIVERS LIVING WITH CHILDREN

When a family member becomes ill or older, it is natural and healthy that other family members will become involved in normal daily household tasks, as well as those extra tasks related to the illness or to the declining abilities of the older person. Often, it is children who step in or who are called on to help in these situations. Caring for an ageing or sick caregiver can help build close and healthy relationships and interpersonal skills which can help the child throughout his or her life, however there is also the possibility that too much responsibility for a child can do more harm than good.

This section provides guidelines for ill or ageing caregivers, so that they can manage the household situation in a way that balances both their own needs, as well as those of the children who take on extra responsibilities.

These guidelines are just that, guidelines. What is possible or “right” in any situation will depend on the availability of community resources and support, as well as on local customs around illness and children’s

roles, and on the children themselves.

A child’s need and right to participate in normal childhood activities.

Every child has the right to go to school, to have friends and to play. Often when caregivers become sick, a child feels responsible for the caregiver and withdraws from his or her friends. In other situations, extra responsibilities are placed on the child so that he or she has no time or no permission to play or to socialise with other children of his or her own age. Such children also need time to care for themselves.

Even though children may be called on to help ageing or ailing caregivers, they should be allowed to participate in as many normal activities as possible. In particular, they should be supported to remain in school and to have time to play. This is one of the best things any ageing or ailing caregiver can do for their children - to help the children cope with this difficult situation.



Every child's need for a supportive and caring adult in their life

Every child needs at least one supportive and caring adult in their life. When the person who most often used to offer this support and love becomes ill or very old, it is easy for roles to be reversed and for the child to feel like it is them, and not their caregiver, who is giving all the care and support. Adult caregivers who become old or sick should not feel guilty about the demands their illness or ageing might place on a child, but they should try and make sure that there is another adult in the child's life for the child to talk to and to receive support from during the time of the illness or ageing.

Appreciation

When children become very sad or depressed as a result of extra responsibilities, it may have less to do with the added responsibilities, and more to do with feelings of not being appreciated for what they are doing.

It is thus very important that other household members, including the ill or ageing caregiver, make the children caring for them feel special, and that their efforts are appreciated. This means thanking them for all they do, asking them "please" to do things, rather than "ordering" them, praising them, and rewarding them wherever possible.

Things for aging or ill caregivers to watch out for that might suggest that the child is not doing so well – plus suggestions about what to do

Child	Suggestion
Worried, sad, anxious, withdrawn, feelings of helplessness, guilt, scared that parents will die	Encourage children to discuss their feelings Explore thoughts about death and life after death Produce memory box, memory book Involve children in planning for the future (succession planning) Give children correct and appropriate information Encourage support from another caring adult
Withdrawal, problems with peers, difficulties with friendships	Reduce responsibilities, allow more time for play with friends and self care Encourage support from another caring adult,
Struggling with school work, deterioration in academic achievement	Encourage children to discuss their feelings Allow time for homework Arrange for extra support via a kid's club, older child, or caring adult
Anger, depressed, withdrawn	Acknowledge child's contribution and child's help, praise, thank, ask by saying please,

EVALUATION OF A MEMORY WORK TRAINING



In October 2003, REPSSI as the host organisation of the Ten Million Memory Project, and the IFRC as a key member organisation, trained 24 participants from South Africa, Lesotho, Botswana, Namibia and South Africa in Memory Work. A year after the training, before any significant additional mentoring or support had been received from REPSSI, an evaluation of this training was conducted by Clacherty and Associates. The evaluation comprised of field visits and telephone interviews. The evaluation was not an impact assessment per se, but rather investigated the rate and extent of transfer of the knowledge received in the initial training.

At the time of the evaluation (October 2004 – February 2005), it was found that all 24 participants had implemented some kind of memory work as a direct result of the training. Most planned and implemented training courses with colleagues or groups of care-workers within 3 or 4 weeks of the training.

By following the cascading trail of all others who had been introduced to memory work as a result of the training, it was found that there were 2298 secondary recipients (those trained or introduced to Memory Work by the participants of the training) and 12700 tertiary recipients (those introduced to Memory Work by the secondary recipients).

The secondary and tertiary recipients included children and youth, caregivers and community workers, work colleagues, family members, clients or PLWAS, parliamentarians, traditional leaders and healers, church groups, social workers, and support group members.

The report concluded, "From the range of very powerful impacts uncovered in this evaluation it is clear that something is working well. The full report includes a discussion on why the tools are so powerful. Some of the reasons include:

- The tools are simple, practical and not complex.
- They seem to be able to survive simplification and

dilution without unduly weakening their value and impact, although there are some concerns around this.

- They are suitable for lay people to use. The memory tools provide volunteers with the means to actualise their instinctive skills.
- Memory work is fundamentally about process, and about using time in an unhurried way so that healing and examination of self can take place so even in non-professional hands, the impact of the training is profound.
- The tools can be adapted and indeed people have taken the tools and adapted them to suit local situations. However, there are some question marks about how much adaptation is good. A concern was raised about the core concept being weakened."

Evaluation of the Ten Million Memories Project Training Workshop held in Cape Town in October 2003, Clacherty and Associates, 2004.

FURTHER READING AND RESOURCES



AIDS Bulletin, Volume 13 Number 2, July 2004.

This special issue of AIDS Bulletin, funded by REPSSI, is devoted to looking at children in the context of HIV/AIDS. It includes five articles about memory work, and several others on orphans and vulnerable children and psychosocial support. They include case studies, analyses and opinion pieces on current work and future directions in this area. It is available free online at <http://www.mrc.ac.za/aids/june2004/contents.htm>, or from: Medical Research Council of South Africa, Corporate Communications, PO Box 19070, Tygerberg 7505, South Africa E-mail: michelle.galloway@mrc.ac.za Fax: +27 21 938 0395

Boxes and remembering in the time of AIDS,

Jonathan Morgan, AIDS Bulletin, Volume 10 Number 2, July 2001.

This article presents an account of the experience of Jonathan Morgan, a writer and therapist, in establishing the Memory Box Project in South Africa. Motivated by the resolve to educate himself about the issues of HIV/AIDS, Morgan invited a group of positive women at the AIDS Counselling, Care and Training (ACCT) organization in Soweto to begin such a project. Just before the July 2000 Durban AIDS conference, the first series of memory box workshops were completed. Some of the boxes were exhibited at the conference and others are still on display

at the Urban Futures Healing exhibit. The article is available from: Medical Research Council of South Africa, Corporate Communications, PO Box 19070, Tygerberg 7505, South Africa E-mail: michelle.galloway@mrc.ac.za Website: <http://www.mrc.ac.za> Fax: +27 21 938 0395

Breaking the silence: memory books and succession planning, the experience of NACWOLA and Save the Children UK in Uganda, Sophie Witter, Save the Children UK, 2004.

This report highlights the work of National Community of Women Living with HIV/AIDS (NACWOLA) in Uganda and Save the Children UK in supporting parents and children to develop memory work. It outlines the successes and challenges of memory books and succession planning in Uganda, looking at the impact of the project on families, and NACWOLA's organisational development. It can be downloaded free from http://www.savethechildren.org.uk/scuk_cache/scuk/cache/cmsattach/1838_Memory%20Books.pdf. It is also available from: Save the Children (SCF) UK c/o NBN International, Estover Road, Plymouth PL6 7PY UK Fax: +44 1752 202333 E-mail: orders@nbninternational.com

Changing children's lives, Healthlink worldwide, 2007.

This publication shares learning from the memory work that Healthlink Worldwide, along with six other non-governmental organisations across sub-Saharan Africa, have developed in response to the HIV epidemic. It examines ways in which memory work provides tools to break through the barriers of discrimination and stigma caused by HIV and AIDS by building strong bridges of communication among children, family members and the wider community.

Child-centred responses to HIV and AIDS: Memory work CD-ROM, Healthlink worldwide, 2006.

This CD-ROM signposts key information and resources on the memory work approach, including training materials, case-studies, background information and reports. It also includes The memory work trainer's manual. This pilot version was produced to coincide with the XVI International AIDS Conference, Toronto, 2006.

Medicus Mundi Schweiz, Bulletin no 97, June 2005.

This issue of Medicus Mundi Schweiz Bulletin is devoted to memory work. Articles describe the evolution of memory books and memory work; NACWOLA's experiences in Uganda;

FURTHER READING AND RESOURCES (CONTINUED)

scaling up memory work; and related projects and tools such as hero books and the Ten Million Memories Project.

The bulletin can be found free online at <http://www.medicusmundi.ch/bulletin/bulletin97.htm>, or is available from: Medicus Mundi Schweiz, Murbacherstrasse 34, Postfach, CH-4013 Basel Switzerland
Tel: +41 061 383 18 10, e-mail: info@medicusmundi.ch

Memory boxes and the psycho-social needs of children: trainer's manual, Sinomlando Centre for Oral History and Memory Work in Africa, School of Religion and Theology, University of KwaZulu-Natal, 2003.

This manual describes a training curriculum designed to give community workers and volunteers a basic understanding of the psychosocial needs of vulnerable children, and basic skills in "memory box" methodology. It is based on a four-day, twelve-session workshop and covers child development, bereavement, loss, stigma, counselling skills and making memory boxes. It is available free online from [http://www.hs.unp.ac.za/theology/sinomlando/MAN%20MB%205%20\(Trainers\)%20REV3.pdf](http://www.hs.unp.ac.za/theology/sinomlando/MAN%20MB%205%20(Trainers)%20REV3.pdf), or from: Sinomlando Centre for Oral History and Memory Work in Africa, School of Religion and Theology, University of KwaZulu-Natal, Private Bag X01, Scottsville, 3209 South Africa

E-mail: denis@ukzn.ac.za Fax: +27 33 260 5858

Strength from Remembering, documentary film by Rene Schraner and Eva Hanger, 2004.

This film, funded by Aidsfocus, documents various memory work approaches including those of REPSSI, the International Federation of Red Cross and Red Crescent Societies, and South Coast Hospice.

The Memory Work Trainer's Manual, HealthLink WorldWide and NACWOLA, 2006.

This manual is for trainers who wish to support parents, guardians and carers affected by HIV and AIDS. It is aimed at trainers with all levels of experience, but does require basic HIV and AIDS knowledge. The training can be delivered to people with varying levels of education and the manual can be adapted to suit local needs. It can also be used to train future trainers to deliver the course.

The River of Hope: Child centred approaches to HIV and AIDS, Healthlink worldwide, 2007.

This is a resource manual for working with children and young people in communities affected by HIV and AIDS. It provides ideas, experiences and practical activities that encourage children to help

each other understand and cope with the impact of HIV and AIDS.

The Ten Million Memories Project, www.10mmp.org

The Ten Million Memories Project (10MMP) is a loose association of memory work practitioners who began to collaborate in 2003. Their website contains an introduction to memory work including a gallery of visual resources and links to several partner organization's websites. REPSSI is the host agency for the 10MMP.

Evaluation of the Ten Million Memories Project Training Workshop held in Cape Town in October 2003, Clacherty and Associates, 2004. www.repssi.org

NOTE: This list of resources draws heavily from The Memory Work Trainer's Manual, which was developed as part of the International Memory Project (see above).

For the full list of Healthlink Worldwide resources see <http://www.healthlink.org.uk/resources/list.html>



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