Memory Box Programme

Sinomlando Project

School of Theology

University of KwaZulu-Natal

Memory Boxes & the Psycho-social needs of children

TRAINERS' MANUAL

2003

FOREWORD

This manual was compiled by Philippe Denis, Sibongile Mafu and Nokhaya Makiwane on the basis of the experience of participators in the Memory Box Programme since its inception in 2000. The Memory Box Programme is one of the components of the Sinomlando Project, a community-based oral history project of the School of Theology, University of KwaZulu-Natal.

The idea of doing memory work with people affected or infected by HIV/AIDS originated in Uganda in the mid 1990s. NACWOLA, an organisation for women living with HIV/AIDS, invited its members to create a "memory book" which provides a framework for parents, relatives or friends to save vital information about the family's background. Today this model is used by various AIDS organisations in Africa. The receptacles for memory work can take many forms: books, boxes, quilts, suitcases, jars, baskets, etc.

In 2001 the Memory Box Programme and Sinosizo Home-based Care, a community organisation in the Durban area that provides AIDS patients and their children with vital support, jointly launched a pilot study to assess the effects of the memory box methodology in twenty Zulu-speaking families. The original mission of Sinosizo was to take care of AIDS patients, but its service providers soon became aware of the equally pressing need to take care of AIDS orphans. From this experimental setting in Durban came the model of intervention presented here.

Since 2002, mostly in KwaZulu-Natal but also in Gauteng province, the Memory Box Programme has trained various NGOs, FBOs and CBOs in the methodology of the memory boxes. Various community organisations have signed partnership agreements with the Sinomlando Project.

This manual is designed for the training of community workers and volunteers assisting families affected or infected by HIV/AIDS. The first section of the training aims at providing a basic understanding of the psycho-social needs of children in need. The second introduces the memory-box methodology.

The authors of this manual found inspiration in the literature, which for many years, in Africa and in the rest of the world, has been devoted to the psycho-social needs of orphans and vulnerable children. They are especially indebted to the manual jointly created by Sinosizo Home-based Care and the Child and Family Centre, University of Natal, Pietermaritzburg in 2000. They have also made use of Bev Kilian's *Sensitisation Programme for Volunteers Offering Psychosocial Support to Vulnerable Children Affected by HIV/Aids, Violence and Poverty* (2nd ed., Pietermaritzburg, 2003).

Mention should be made of the parents, caregivers, relatives and family friends who have contributed to the development of the methodology of memory boxes by being prepared to share their memories as a way of enhancing the resilience of their children. Furthermore, one needs to acknowledge the role of the community workers and volunteers who assisted these families and of the various professionals who advised and supported the authors of this manual.
Lastly, we would like to express our gratitude to the *Swiss Catholic Lenten Fund*, the *Secure the Future Foundation* (Bristol-Myers and Squibb), the *Catholic Medical Missionary Board*, the

Comité Catholique contre la Faim et pour le Développement, *HopeHIV*, *Aids and Child*, and the *Anglo-American Chairman's Fund* for the financial support they have given ,or are still giving, to the Memory Box Programme.

November 2003

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GENERAL INTRODUCTION

1. PURPOSE OF THE MANUAL

The purpose of this manual is to give community workers and volunteers:

a) a basic understanding of the psycho-social needs of children in need

b) basic skills in memory- box methodology

2. MATERIAL

The **facilitators** bring with them:

– chart paper
– koki pens, Prestik, cellotape
– an overhead or data projector
– paper and crayons
– a water jug and glasses

The **trainees** are provided with:

– a folder
– a name tag
– a copy of the manual
– writing material
– a consent form
– an evaluation form

3. ENERGISERS

Suggestions:

– Ball games
– Fruit salad
– Coconut
– Blind walk
– Fly fly
– River bank

4. OUTLINE OF THE WORKSHOP

DAY ONE	DAY TWO	DAY THREE	DAY FOUR
Session 1 Introduction 1. Getting started 2. Aims of the workshop 3. Structure of the workshop	**Session 4 Dealing with loss** 1. My experience of loss	**Session 5 Memory** 1. Memory boxes 2. Resilience	**Session 6 MB methodology** 1. Introducing the method 2a. Practising the method (Exercise 1)
		Tea	
Session 2 The context 1. Community profile 2. Health, Disease, HIV/AIDS and death 3. Talking about HIV/AIDS	**Session 4 Dealing with loss** 2. Feelings associated with loss 3. States of bereavement 4. Children and death	**Session 5 Memory** 3a. Memory work (Exercices 1-3)	**Session 6 MB methodology** 2b. Practising the method (Exercise 2) 3. Understanding the process
		Lunch	
Session 3 The needs of the child 1. Understanding the needs of children 2. Stages of development	**Session 4 Dealing with loss** 5. Child Bereavement Counselling	**Session 5 Memory** 3b. Memory Work (Exercise 4)	**Session 6 MB methodology** 4. Creating a memory box **Session 7 General evaluation**
		Evaluation - Closure	

DAY ONE

SESSION ONE

Introduction

Objective By the end of this session the participants should agree on a code of conduct for the workshop and commit themselves to respecting it. They should also be able to show that they understand the aims of the workshop.

1. Getting started

a) Prayer or greetings

b) Introducing each other

Suggestion: The trainees introduce themselves to their immediate neighbour. The neighbours share with the group what they have understood from the presentation.

c) Clarifying and discussing expectations

d) Timetable and transport arrangements

e) Agreeing on a code of conduct

Suggestions Punctuality
No cell phones
Sensitivity to others' feelings
Preparedness to listen to each other

2. Aims of the workshop

a) The first aim of the workshop is to have a basic understanding of the psycho-social needs of the children. This is a condition for doing memory work with children.

In brief: **WHO** can benefit from the memory boxes?

b) The second aim of the workshop is to raise awareness about the importance of memory in the family. People who deal with their emotions, who talk about their feelings and make space for bereavement cope better in difficult situations. This is why memory boxes are useful.

In brief: **WHY** have memory boxes?

c) The third aim of the workshop is to learn how to make memory boxes.

In brief: **HOW** to make memory boxes?

3. Structure of the workshop

DAY ONE: understanding the **context** in which the memory box methodology will be implemented with particular reference to **needs of children**.

DAY TWO: understanding and practising basic **bereavement counselling** skills

DAY THREE: observing, analysing and reflecting upon existing **memory** practices in the families. This section looks at the past.

DAY FOUR: promoting new memory practices in the families by way of the **memory box methodology**. This section looks at the future.

TEA

SESSION TWO

The Context

Objective	By the end of this session the participants should be able to show that they understand the context in which they will do memory-box work. This includes a basic understanding of health, AIDS, illness and death

1. Community profile

In this section the participants will draw up the profile of the community in which they will operate. Even though the different communities seem similar, there are differences. The participants needs to be aware of these differences. One cannot assume that everybody experiences the same problems and has the same resources.

Exercise **The community profile of my community**

Objective Developing a greater awareness of the needs and resources of my community

Task Describing my community:

Method The participants are divided into small groups. Each group answers the following questions:

– What is the name of the community?
– What kinds of houses?
– How many people live there?
– Are there any crèches? If so, how many?
– Are there any recreation facilities? If so, how many and where?
– Who are the community leaders?
– Are there any churches? If so, how many and where?
– What kind of transport is available?

If possible, the participants draw a map of their community, indicating the roads, rivers, creches and churches.

2. Health, disease, HIV/AIDS and death

In this section the participants will share their understanding of health, disease, HIV/AIDS and death respectively . These concepts may have different meanings for different people. In certain cultures, for instance, health is understood holistically: there is more to being healthy than simply not being sick.

Exercise **Multi-cultural understanding of health, disease, HIV/AIDS and death**

Objective Discussing the different meanings of health, disease, HIV/AIDS and death among the participants.

Task Defining the meaning of the following four concepts:
– health (*impilo*)
– disease/sickness (*isifo*)
– HIV/AIDS (*ingculazi*)
– death (*ukufa*)

Method The participants are divided into small groups. For each of the four concepts, the groups answer the following questions:
– What is it?
– How does one get it?

– Why does one get it?

The answers are written on a flip chart and displayed on the walls.

If time is limited, the facilitators may ask each group to discuss only one concept.

When the exercise has been completed, one member of the group presents the group's flip chart to the participants.

3. Talking about HIV/AIDS

In this section, the participants will describe how HIV/AIDS is perceived in their community. Almost everywhere, it is difficult to talk about HIV/AIDS. Why?

Exercise **Why people are reluctant to talk about HIV/AIDS?**

Objective Better to understand why communities are reluctant to talk about HIV/AIDS

Task To list the reasons which prevent people from talking openly about HIV/AIDS

Method Each participant receives a pen and a few small pieces of paper. On these pieces of paper they write what they think are the reasons why people do not talk openly about HIV/AIDS.

When this task is completed, the participants stick the pieces of paper onto a flip chart with Prestik. They are invited to group the pieces of paper according to themes.

A general discussion of the causes of the silence around HIV/AIDS concludes the exercise. The participants are invited to compare their views on this subject. Are the difficulties the same in all communities?

LUNCH

SESSION THREE

The needs of the child

Objective By the end of this session the participants should be able to show that they understand the developmental stages and basic needs of the children

1. Understanding the needs of children

In this section the participants will learn how to identify and classify the needs of children. All children are considered, whether vulnerable or not.

Exercise **Brainstorming the needs of children**

Objective: Understanding the various needs of children.
Task : Drawing up a list of children's needs and classifying these needs into broad categories

Method The participants brainstorm the needs of children. The facilitators write the answers on a flip chart.

As they mention children's needs, the participants are invited to classify them. Examples of categories are: physical, emotional, social, cognitive and spiritual.

Children's Needs

Children have needs, all of which are equally important. Any unmet need will cause malfunctioning in the child.

Physical needs

Children have many physical needs such as food, clothing, shelter, school-related expenses inoculations, health care and hygiene. The simple provision of financial needs is NOT sufficient for children to grow up to be healthy, well-adjusted people.

Emotional needs

Children need to love and be loved, to accept and be accepted, to have security, encouragement, recognition from others, self-confidence and positive self-esteem. They need to be able appropriately to trust themselves, others and the world around them. Children need to be heard, to speak to others and to feel that they count as individuals. They need to be listened to and to be understood before they can understand.

Social needs

Humans are essentially social beings. They have to live among others. No one is an island. We need to feel that we belong in our families, and our communities, and that we are part of a cultural and national group. It is important to have a sense of identity and belonging. We do not like to feel different and to be discriminated against. Much of our behaviour is learnt within social situations – with our parents, families, friends and communities.

Cognitive needs

There are three main categories of cognitive needs: (i) formal education where we are taught from early childhood what we need to know in order to survive within an industrialised society; (ii) informal education where we learn by observing others, seeing what reactions other elicit, setting our own goals, dreams and ambitions and learning what it takes to be a part of a particular community ("we do things this way"); (iii) general skills like life skills and general knowledge (for example a child may be given a bag of sugar beans, but without knowing how to cook the beans and that beans are a good source of protein, he or she will not know their value).

Spiritual needs

It is through our beliefs that we develop a sense of hope. Practising our faith in times of hardship enables us to cope better. It gives us a sense of purpose and enables us to see beyond the hardships of present life circumstances.

(adapted from: Bev Killian, *A Sensitisation Programme for Volunteers Offering Psychosocial Support to Vulnerable Children Affected by HIV/Aids, Violence and Poverty. Participant's Manual.* 2nd edition, Pietermaritzburg: University of Natal, January 2003, p. 20-21.)

2. Stages of development

In this section the participants learn how to identify the needs of children according to age groups. All children are considered, whether they are experiencing grief or not.

Exercise **Understanding the stages of development**

Objective Understanding that children of different age groups have different needs.

Task Identifying and classifying the needs of children according to their age groups.

Method The participants are divided into small groups. Each group identifies and classifies the needs of children on a flip chart, according to their age group.

When the exercise is completed, the flip charts are displayed on the wall and a representative of each group presents them to the other participants. A discussion follows.

Ages and Stages of Development

We can divide the growing process into developmental stages roughly on the basis of individual ages.

- # Infants and toddlers:0-2 years
- # Pre-school children: 2 to 6 years
- # Young children: 6 to 8 years
- # Pre-adolescents: 9 to 12 years
- # Adolescents: 13 to 18 years

(Sharon Lewis, *An Adult's Guide to Childhood Trauma. Understanding traumatised children in South Africa.* Cape Town: David Philip, 1999, pp. 149-53).

Homework

In preparation for the work of the last day, the facilitators ask the participants to create a memory box when they return home. This can be done with the help of the other members of their family.

EVALUATION - CLOSURE

DAY TWO

SESSION FOUR

Dealing with loss

Objective	By the end of this session the participants should be able to show that they understand the feelings associated with loss and know how to help children to deal with these feelings.

1. My experience of loss

In this section the participants are invited to reflect on their own experience of loss. Most of us have experienced a loss. For some it has been, and still is, very painful. But we know from our own situation what helped us to cope and what made it more difficult. Our experience is a valuable tool when we start helping others who have suffered losses.

Loss, Bereavement, Grief and Mourning

Most of us have experienced the **loss** of a dear one. Death is indeed the most common cause of loss, but we also experience loss through divorce, separation or abandonment.

When we suffer loss, we go through a stage of **bereavement, a** word that refers to "the objective fact that a meaningful person has died". Bereavement is usually accompanied by stress.

The loss of a dear one causes **grief**. This word refers to "the sequence of subjective states that follow loss".. Grief is a process, rather than a specific emotion like fear or sadness.

To overcome grief, we go through a process called **mourning**. This word refers to the "mental work following the loss of a loved object through death". This mental work, also called grief work, involves the painful, gradual process of coming to terms with loss

(adapted from Nancy Boyd Webb (ed), *Helping bereaved children. A Handbook for Practitioners* .New York: Guildford Press, 1993, pp. 7-8.)

Exercise	**Remembering somebody we have lost**
Objective	Reflecting on our experience of loss and describing the feelings associated with this experience
Task	Sharing with the other members of the group an experience of loss

Method The facilitators invite the participants be relaxed and to sit comfortably. They ask them to close their eyes and recall an experience of loss:

"Try to remember a person whom you lost. It may be a loved one or someone you just knew. Try to remember the time before the person died. Was the person sick? What type of feelings did you have during this time. Try to remember the day the person died. Who told you? How were you told? How did the way you were told affect you? Try to remember the feelings you had immediately after this person died. Try to remember what happened after the death. How did you feel? What customs or rituals were followed? Did you go to the funeral? How did you feel during the funeral? How did you cope over the next few weeks, months or even years? Do you still have sad feelings when you think of the person? Did your feelings change over time?"

A few minutes later the facilitators ask the participants if they are ready to open their eyes.

The facilitators invite the participants who feel free to share their experience of loss to do so. Nobody is obliged to speak. Those who choose to share their experience are invited to describe their feelings and any rituals or customs performed at the time of the death.

The facilitators monitor the emotions of those who share their experience of loss and thank them for their participation. This exercise requires sensitivity and compassion.

TEA

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2. Feelings associated with loss

In this section the participants identify and describe the various feelings associated with loss

Exercise: Feelings associated with loss

Objective Helping participants to see that death involves a wide variety of feelings. Individuals' feelings, when they are intense, tend to oscillate regularly and often uncontrollably.

Task To identify the feelings associated with loss

Method The participants brainstorm the feelings associated with loss. The facilitators randomly write the answers on a flip chart.

The facilitators ask the participants if the feelings described on the flip chart are also experienced by children. This is followed by a general discussion on children and grief.

3. Stages of bereavement

According to the psychiatrist Elisabeth Kubler-Ross, there are five stages in the process of bereavement: denial, anger, bargaining, depression and acceptance.

The facilitators invite the participants to share their ideas on the stages of bereavement. The answers are written on a flip chart. The facilitators verify that the five stages of bereavement are identified by the group.

The five stages in the bereavement process

1. The first stage is **denial** "No, not me!" This is a healthy stage, and permits the person to develop other defences.
2. The second stage is **anger** or resentment. "Why me?" is the question asked now. Blame is directed against the family, the neighbours, the doctor or even God.
3. The third stage is **bargaining**. "Yes, but..." The person tries to imagine what he/she should do to have the deceased back into the family.
4. The fourth stage is **depression**. Now, the person says, "Yes, me!" with the courage to admit that the death has happened. This acknowledgment brings sadness and depression.
5. Finally comes **acceptance**. The person faces death calmly. This is often a difficult time. He/she tends to withdraw, to be silent.

(adapted from:Elisabeth Kubler-Ross, *On death and dying. New-York: Macmillan, 1969.)*

4. Children and death

When someone close to the child dies, the child will be emotionally distressed and will express this in a number of ways. This section deals with children's response to the death of a significant person in their lives.

The facilitators invite the participants to brainstorm on the ways in which children express their grief. The answers are written on a flip chart.

How do children grieve?

- # Initial shock and denial
- # Expecting the deceased person to return
- # Fear and insecurity
- # Being overly conscientious and compliant to gain support
- # Being naughty to attract attention
- # Being clinging and dependent
- # Regressing
- # Idealising the deceased person
- # Sadness
- # Guilt
- # Anger
- # Feeling different, or ashamed
- # Somatising physical symptoms without there being a medical cause
- # A lack of concentration at school
- # Re-enacting the circumstances of the death and the funeral.

(adapted from: Lewis, *Adult's Guide to Childhood Trauma.*, pp. 153-57)

LUNCH

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5. Counselling bereaved children

One does not need to be a professional therapist to help a child in grief. Any community worker, church worker or adult of good will can provide support to the child. In this section the participants will learn some basic principles in bereavement counselling for children.

The purpose of counselling bereaved children is to provide opportunities for their expression of thoughts and feelings. It is also to prepare the children for the responses and problems they are likely to face.

Exercise 1 **Video**

Objective: To acquire basic counselling skills

Task: Watching a video and discussing its contents

Method: The participants watch a video that shows showing examples of the counselling of bereaved children. When the play is over, the facilitators invite the participants to comment on the video.

Exercise 2 **Role-play**

Objective: Learning how to counsel bereaved children

Task: Role-play

Method: The facilitators provide basic information on the counselling of bereaved children (see chart below). A brief discussion follows.

Once the facilitators are satisfied that the participants have understood the presentation, they invite them to role-play a situation in which a community worker provides counselling to a child in grief.

The other participants observe the role-play and share their comments.

The exercise can be repeated several times.

A model for bereavement counselling

This model which can be used to help children who need help whilst in the bereavement phase:

1. Creating a nurturing environment

- # Children need a sense of safety and security in order to share their fantasies and fears about death.
- # Children need to know that the counsellor will not tell anyone what they are discussing. The conversation is confidential.
- # Good counsellors are non-judgmental and honest. Their body language shows that they have an open attitude. They are empathetic, and try to understand what the children are experiencing.

2. Active listening

- # Good counsellors are active listeners.

- # They help the children to give words to their sorrow.
- # They give verbal and non-verbal cues to show that they understand and are listening.
- # From time to time, they restate, in their own words, their understanding of what the children are feeling. Having one's feelings understood, accepted and tentatively put into words can be a very affirming experience.
- # Children's questions should be answered immediately, honestly and factually.

3. Acknowledging and validating feelings

- # The role of the counsellor is to normalise the children's feelings of anger, sadness, fear, etc.
- # By confirming and ratifying what the children say, the counsellors help the children to regain a sense of control over their own feelings.
- # Bereaved children develop poor self-esteem. Counsellors will show appreciation for the fact that the children have been able to survive, as best they could, a difficult situation. They will help the children to recognise their own gifts.

4. Addressing fears

- # Children have many fantasies about death. Sometimes they imagine that they caused the death of the loved one. They need to feel safe to share their fantasies and to be reassured that they did not cause the death.
- # Children need to be reassured that the surviving caregivers are not necessarily going to die.

5. Providing opportunities to say good bye

- # Counsellors can invite the children to develop rituals or symbols to say goodbye to their deceased parents and express their love for them.
- # This is particularly important when the children have not attended the funeral.

6. Helping to adjust to a new life

- # The children suffer a double loss. Often, they do not only lose a parent; they also lose their home, their school and their friends. Their basic needs are not provided in the same way as before.
- # The role of the counsellor is to help the children enter into their new lives. Where will they live? How will they get to and from school? Who will cook for them and who will provide them with clothes?
- # At this stage it may be advisable to involve other members of the family in the counselling session.

(adapted from: Sinosizo Home-based Care / Child and Family Centre, University of Natal,

Pietermaritzburg. *Introduction to the psycho-social needs of children. Facilitator's Training Programme Guide*, n.d. [2002].)

Homework

In preparation for the work of the third day, the facilitators ask the participants to draw a family tree. This task can be achieved with the help of the other members of their family.

EVALUATION - CLOSURE

DAY THREE

SESSION FIVE

MEMORY

Objective	By the end of this session the participants should be able to show that they understand how memory work enhances resilience in children in grief.

1. Memory Boxes

In this section, the participants are introduced to the concept of the memory box.

The facilitators invite the participants to share what they already know about memory boxes. A discussion takes place during which the following issues are clarified.

a) What is memory?

Memory is the ability to bring back to consciousness past events.

b) What is a memory box?

A **memory box** is a physical object created by the family and/or the children for storing letters, photographs, tapes or any object related to the history of the family.

The purpose of memory box methodology is to build up **resilience** in children. Resilience is the ability to cope in difficult situations such as disease, death, abuse or crime.

c) Who can benefit from the memory boxes?

The memory box methodology has proved to be effective with children who have a parent or loved one with HIV/AIDS or any other life-threatening disease.

Two types of **situations** can arise:

(i) The parents of the child are sick or they expect to be sick some time in the future (pre-death situation)

(ii) The parents of the child have died, and the children are in the care of a grand mother, another relative or a caregiver external to the family (post-death situation).

d) Who is in involved in the memory box process?

Four types of people are involved, or can be involved:

(i) The **adults** in the family

(ii) Their **children**

(iii) The **internal memory facilitators**. who visit the family and propose their assistance. A memory facilitator is a person who assists the family in retrieving their memories, especially when the memories are painful. The internal memory facilitators are usually social workers or volunteers . They belong to a community-based or a faith-based organisation. They play various roles, providing home-based care, orphan support, remedial teaching, etc. They are the ideal people for helping the family to retrieve their history.

(iv) The **external memory facilitators** who are specialised in memory facilitation and come at the invitation of the organisations employing the community workers. Their intervention is intense but short-lived. They need to be introduced to the family by the volunteers. For the method to succeed they must carefully explain their role to the volunteers and to the family.

2. Resilience

In this section the participants will explore the concept of resilience. As mentioned earlier, resilience is the ability to cope in difficult situations arising from disease, death, abuse or crime. The purpose of memory box methodology is to build up resilience in children.

To explain the concept of resilience, the facilitators use an elastic. They invite the participants to stretch the elastic to its extreme limits and ask them what they have observed. They explain that in the same way adversity stretches the capacities of the children to their limits. They need support to return to normality.

Resilient children have:

external support and resources: “I have....”
internal strengths: “ I am...”
social and interpersonal skills: “I can....”

Indicators of resilience

I have...

- Trusting relationships
- Role models
- Encouragement for autonomy and independence

I am...

- Lovable and my temperament is appealing
- Becoming autonomous and independent
- Proud of myself
- Filled with hope, faith and trust

I can...

- Communicate
- Solve problems
- Manage my feelings and impulses
- Seek trusting relationships.

(Edith Grotberg, *A guide to promoting resilience in children: strengthening the human spirit.*. The Hague: Bernard van Leer Foundation, 1995, pp. 42-3).

Exercise:	**A case study of resilience**
Objective	Understanding, by way of an example, how resilience functions
Task	Analysing a case study
Method	The participants are divided into small groups. Each group analyses one case study. On a flip chart they record the risk factors and resilience factors involved in the story. Once the exercise is completed, the flip charts are displayed on the wall. A general discussion follows.

Case study

Since the disappearance of her daughter, it is Nonjabulo who is raising Bongani and Mandla, her two grandsons, aged sixteen and thirteen respectively. Dulcie had died of Aids a year before our first visit. They had not heard from the boys' father for several years. Nonjabulo and the two boys live on the third floor of a dilapidated building. At each of our visits, we were interrupted by the children who had come to sell sweets. It is the meagre profit from the sale of sweets that sustains the family. Nonjabulo is tired. At an age when one would wish to rest, she must care for two adolescents. The older one is always out. She wonders whether he is taking drugs. His school marks are mediocre. Nonjabulo is afraid that the younger may follow in his older brother's footsteps.

We presented ourselves as memory facilitators. We visited the family in the company of Margie, a volunteer from a community-based project. Nonjabulo appreciates the volunteer's visits. The two women had met in the palliative care facility when Dulcie was dying.

Our first visit did not go smoothly. The grandmother complained of a shortage of money, of her backache, of the unruliness of the children. What good had come of the death of her daughter? The two children maintained a stony silence. The older evaded our glances. However, little by little, we established a connection.. On the second visit, sensing resistance on the part of the two children, we suggested that they write a story about their mother. They agreed that that sounded like a good idea. The following week Bongani had written a poem and Mandla a description of good times he had had with his mother. We found out later that he had decorated a box in which he saved all the objects that reminded him of his mother. But he did not show it to us on that day.

The ground had been laid for the interview, the decisive moment of our intervention. This took place during the fourth visit. It was Margie, the volunteer, who spoke first. The grandmother chose to stay in the background. From the kitchen, she observed the scene without speaking. Soon, however, she approached the circle. She was finally the one who spoke longest. She told about Dulcie's childhood, her time at school, her first job, the birth of her children, and the onset of her illness and eventual death. The final part of her narration was very moving. With the permission of the participants, the conversation was recorded. The two children also told their stories, but more briefly.

The next stage consists of transcribing the interview, editing it and giving it to family members to correct certain details and to add their comments. Nonjabulo brought us a photo of her daughter which we scanned and inserted into the folder containing the interview.

We had reached closure. We solemnly returned the folder to the two children. For the first time since we began visiting the family, Nonjabulo offered us tea. Contrary to her habit, she did not complain of her aches. The atmosphere was warm. We asked the children what they thought of our intervention. They replied that they felt freer. They then knew how to talk about the death of their mother. Their grandmother also expressed her happiness. She called a friend to show her the folder which she described as if it were a treasure.

The story of Bongani and Mandla	
Risk factors	Resilience factors

TEA

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3. Memory work

In this section the participants are invited to reflect on the role memory plays in their lives. This will help them to do memory work with families in grief.

Exercise 1 I remember

Objective By the end of the exercise, the participants should be able to show that they understand the importance of memory for themselves and for their own families.

Task To explore how we remember important events and important people in our lives.

Method The participants are divided into small groups. They share their experience of memory, that is:

a) what they remember

Examples: a wedding, the death of a family member; a forced removal, the graduation of a relative.

b) on what occasions they remember

Examples: at certain family gatherings; when they are alone; when their children ask questions.

c) how they remember

Examples: with joy, painfully, only when are surrounded by caring people.

d) what impact the fact of remembering has on them

Examples: relief, peace, sadness, distress.

Exercise 2 Family tree

Objective By the end of the exercise, the participants should be able to describe the history of their family and explain what it means for them.

Task Drawing up a family tree

Method The participants are divided into small groups. They present the family tree they have drawn up at home the night before (see above: homework) to the other members of the small group. Each group decides which family tree will be presented to the main group.

Alternatively the participants can display their family trees on the walls. The members of the other groups are invited to look at them.

After the presentation of the family trees to the main group, the facilitator asks the participants how they feel, having drawn their family tree. This can be an emotional exercise.

Examples of comments: "I never realised that I knew so little about my grandfather!" "Why did my mother hide from me that she had a child before she met my father?" "In my family my aunt plays a bigger role than my mother."

Exercise 3 After my death

Objective By the end of the exercise, the participants should be able to show that they understand what it means for people living with a life-threatening disease to be faced with the prospect of dying at a young age.

Task Reflecting on the following question: "How would we like our children to remember us when we die?"

Method The participants are asked to close their eyes and imagine that they are dead. How would they like their children to remember them? The facilitator warns that the exercise can be emotional and may sound frightening.

After ten to fifteen minutes volunteers are invited to give a brief feedback on this experience. The facilitators affirm the participants as they share their experience.

LUNCH

Exercise 4 Skills transfer

Objective By the end of this exercise, the participants should be able to demonstrate their ability to apply the skills learned during the morning session to their ordinary work with the families

Task Helping the families affected by HIV/AIDS to remember their histories.

Method: In the morning the participants are asked to reflect on their own way of remembering. Now they have to imagine how the families with whom they are working deal with their memories.

The participants are divided into small groups. They choose one of the families they are caring for, and try to imagine how they would do the same three exercises with them.

Each small group presents a report to the other participants.

EVALUATION - CLOSURE

DAY FOUR

SESSION SIX

MEMORY BOX METHODOLOGY

Objective	By the end of this session the participants should be able to use the memory box methodology with a family.

1. Introducing the method

By the end of this section, the participants should be able to demonstrate a basic understanding of the memory box methodology. They will show that they know how to help families to create their memory boxes.

Note: The full method comprises eight steps. For various reasons the process sometimes remain incomplete. Memory facilitators should not be distressed if the process is arrested. This will only mean that the family is not ready to look at its history at that particular moment. The important is to initiate a process of dialogue in the family.

Step-by-step introduction to the memory box methodology	
Step 1	Initial conversation about memory boxes
Step 2	Introducing the memory box methodology. Verifying that all the family members are involved in the process and that they give informed consent.
	Note: This part of the process takes time. Several visits can be necessary.
Step 3	Creating and/or decorating the memory box (with the participation of children) as a container for the letters, photos, documents and other objects to be collected at a later stage of the process.
Step 4	Collecting significant objects (letters, IDs, old photos ...).
Step 5	Taking pictures of the family members and/or of sites of significance to the family history. If possible, this should be done with a camera belonging to the family. If not, a camera belonging to the organisation can be used. A digital camera is best, to allow low-cost reproduction of the photographs.
	When proposing to take pictures, it is important to be sensitive to the feelings of the family members.

Step 6	Inviting the parents/caregivers/children/other family members to write their stories. They can choose the form of a letter addressed to the deceased person or of a "memory book" in which they chronicle the main events of the family history. In doing so, they make use of a set of guidelines provided by the memory facilitators. They can also draw a family tree. The documents thus created are placed in the memory box.	
Step 7	Interview. At this stage, the memory facilitators propose to choose one of three methods:	
	Method A:	Family members, family friends or volunteers tell the history of the family in the presence of the children. If they have written a "memory book", they are invited to refer to it. No tape recorder is used. The memory facilitator or another person who has writing skills (e.g. a high school child, teacher or priest) takes notes during the conversation.
	Method B	Tape recording of the conversation for the use of the family but without transcription.
	Method C	Tape-recorded interview. This is a fairly long process, which normally necessitates the assistance of an external memory facilitator. The assistance of an experienced person recommended by the organisation such as teacher, a priest or a professional secretary can also be of help.
	Once the interview has been conducted, the following tasks need to be accomplished:	
	!	Verbatim transcription of the tape in the original language
	!	Editing the transcript to make the story fluent and easy to read.
	!	Insertion of photos into the edited transcript. The use of a digital camera makes this operation much easier.
	!	Presentation of the draft edited version to the family for comments.
	!	Revision of the edited version.
	!	Presentation of the final draft to the family.
	For the interviews a **semi-structured questionnaire** is recommended, that is, a set of questions which guide the memory facilitators during the interview, while allowing space for further questions. As the conversation moves on, the memory facilitators ask questions which were not included in the original questionnaire. They allow the family members to say what they have in their hearts	

	The interview should be very broad. It is about the **life story** of the children's parents or relatives. Inevitably some questions will concern the sickness and possibly the death of the parents, but topics such as the early childhood, education, holidays, first job, professional career and hobbies of the family members should also be addressed.
Step 8	Closure
	The purpose of the closure is to get the memory facilitators and the family jointly to evaluate what has been achieved with the memory box process. The intervention is officially ended and a discussion on the way forward takes place.
	Depending on who has conducted the process, there are two types of closure:
	a) With external facilitators: farewell and handing over to the volunteers.
	b) With internal facilitators: closure of the memory box process and discussion of the follow up.
	(based on Philippe Denis et al., *Sharing family stories in times of AIDS. Pilot study report*, March 2002. <www.hs.unp.ac.za/theology/sinomlando>)

2. Practising the method

In this section the participants role-play the implementation of the memory box methodology in the families. Each role-play is discussed in the group. The facilitators provide any additional information that is needed. The different concepts introduced in this manner are written on a flip chart.

Exercise 1 Introducing the method

Objective By the end of this exercise, the participants should be able to demonstrate their ability to introduce the memory- box methodology to a family.

Task Role-playing the introduction of the memory box methodology to a family

Method Three or more participants role-play memory facilitators or volunteers who introduce the memory box methodology to a family.

Roles:
a) memory facilitators or volunteers (2)
b) parents or caregivers (1 or 2)

c) children (any number)

The ages of the children should be specified beforehand. Those who play the children need to play as children and not as adults.

TEA

Exercise 2 Interview

Objective By the end of the interview, the participants should be able to demonstrate their ability to conduct an interview with a tape recorder.

Exercise Conducting an interview.

Method: Three small groups. They prepare a draft questionnaire and conduct an interview among themselves.

Brief report to the plenary session.

Material: at least three tape recorders.

3. Understanding the process

When the role-plays are completed the facilitators check that the following concepts are understood by the participants.

Theoretical issues

1. Which do you think is the **right time** for an intervention? Is it time

– to encourage the family members to share the story of the family with the children? What happens if all the children are scattered as a result of the death of the parents?

– to encourage the parents to disclose their HIV status to their children?

2. How do you see your **role** and your **motives**? How far to you think you can go when discussing family issues? Where do you set the **boundaries**? Different types of people, all playing different roles, visit the family:

– doctors, nurses or medical professionals

– social workers

– priests, ministers or church agents

– memory facilitators.

3. How do you deal with the **expectations** of the family?

In a context of poverty, families tend to expect material support from any external visitor. Yet memory facilitators cannot provide this type of support. They can only channel the requests of the families to the relevant persons or institutions.

4. How do we verify that the family has given informed consenIt takes time before a family fully understand the purpose and the implications of the memory box process. It is not unusual to have to repeat the same message several times..

5. Have you explained the importance of **preserving** the memory boxes and the material that is contained in them?

Where will the family keep the box? What will happen if they move? Is the material used durable enough to resist the ravages of time?

6. How do you understand the **confidentiality** needed for the process? How do you deal with **privileged information**?

Family members are afraid of disclosing private information to outsiders. This is understandable. The issue of confidentiality needs to be discussed openly between the memory facilitators and the family members. An atmosphere of trust needs to be built if the memory box process is to be successful.

HIV/AIDS makes the matter even more difficult. Because of the stigma attached to the disease, people living with HIV/AIDS do not readily disclose their status. A great deal of sensitivity is needed here.

Present and discuss a vignette on the difficulty of disclosing one's HIV status to one's family.

7. Who needs to be involved in the family? What are the **family dynamics**? Is there any power problem? What about **family secrets**?

8. Is all of this possible within the context of **African culture**?

Are children allowed to ask questions in the family? What happens to them when the family is grieving? Who talks to the children about the death of their parent? Are they involved when a decision concerning their future is made?

9. How do you feel after having been involved in the interview? How do you deal with your **emotions**? With those of the family members?Examples of emotions: anger, confusion, helplessness, sadness.

10. What sort of **support structure** do you rely on? Is any further support needed? Can

prayer play a supportive role?

Examples of support structures: talking to a friend, visiting a minister, praying, phoning Child Line.

(based on Philippe Denis et al., *Sharing family stories in times of AIDS. Pilot study report*, March 2002. <www.hs.unp.ac.za/theology/sinomlando>)

LUNCH

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4. Creating a memory box

In this section the participants present the memory box they created at home on one of the first days of the workshop (see above: day one, homework).

With material found at home, the participants constructed a memory box. During the session, the participants explain how they made their memory boxes and what they put into them.

SESSION SEVEN

GENERAL EVALUATION

The facilitators ask the participants to answer the following questions:

1. Evaluation of the workshop

    a) What struck you in the workshop?

    b) Do you anticipate that problems will arise when you introduce the memory box methodology to families?

2. Recommendations for further workshops.

3.. Date for a follow-up workshop.

CLOSURE

FOLLOW-UP EVALUATION WORKSHOP

Format: two sessions, preferably one month and three months after the workshop

1. Reports by the volunteers on their work with the families

1.1 Understanding of the project

a) Do you have a clear idea of your task as a memory facilitator?

b) How do you relate this task to your work as a community worker?

c) Have you been able to reorganise your work to include memory work with the families?

1.2 General skills

a) Are you able to explain the memory box process to a family. Give an example.

b) Are you able to record a family story. Give an example.

c) Are you able to assist a family in creating a memory box? Give an example.

1.3 Quantitative evaluation of the memory work done with the families

a) How many families do you regularly visit?

b) To how many families have you introduced the memory box methodology?

c) How many families do you think are ready to start the process?

d) How many families have already created a memory box?

e) How many families have already started sharing family stories?

f) How many families have already started recording their stories (in writing or otherwise)?

1.4 Difficulties and challenges

a) Did you experience emotional difficulties or challenges in doing memory work with the families? How have you dealt with your own emotions?

b) Did you encounter any resistance or hesitation on the part of the families?
Examples: monetary expectations; fear of family members or neighbours, sickness.
How did you deal with resistance?

c) Did you experience any difficulties or challenges on the part of your organisation?
Examples: catering, tape recorders, transportation, work overload, recognition.

1.5 Support

a) What sort of support would you need?

2. Recommendations

a) Support structures for volunteers

b) Follow-up meetings (eg monthly meetings of volunteers)

c) Material

d) Any other recommendations

3. Evaluation of the follow-up workshop

3.1 Evaluation of the number of volunteers present at the evaluation meeting. If some are absent, what is the reason? Does it mean that they were not interested in the memory box methodology? Or was there some other reason why they did not attend the evaluation meeting ?.

3.2 Evaluation of the reports presented by the volunteers