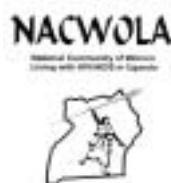


# THE MEMORY WORK TRAINER'S MANUAL

supporting  
families affected by  
HIV and AIDS





# **The memory work trainer's manual: supporting families affected by HIV and AIDS**

This manual has emerged from experience of memory work in Africa. It is intended as a template that can be adapted for use in different settings. It is a work in progress. Your feedback will help us to improve the manual.  
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The photographs in this manual were taken by, and are copyright of, Georgina Cranston for Healthlink Worldwide, and Healthlink Worldwide staff. They are of people who are involved in projects with Healthlink Worldwide's partner organisations in Kenya and Uganda.

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## Preface

Memory work is a community-led approach to encourage families to communicate openly about HIV. It helps parents look at how to disclose their HIV status to their children, record important information in ‘memory books’, and plan for the future.

Barnardo’s (UK) began working with memory books in the 1990s with African families affected by HIV and AIDS in the UK. Since then, memory work has come a long way. NACWOLA (the National Community of Women Living with HIV and AIDS) in Uganda, Save the Children Uganda and CLS Development Services have contributed significantly to its development. These organisations worked to develop the approach so that it could be used on a larger scale, and to widen it from its initial focus on producing memory books.

This manual has emerged from the International Memory Project, funded by Comic Relief, through which Healthink Worldwide and NACWOLA have introduced NACWOLA’s pioneering approach to other organisations in Africa.

The memory work approach is designed to evolve, responding to the changing needs and circumstances of communities – for example, the increasing access to antiretroviral therapy. However, the focus of memory work on disclosing of HIV status and improving communication between parents and children remains key in an environment where people are living longer with HIV.



Members of NACWOLA perform a song about HIV and AIDS

# Introduction for the trainer

The Memory Work Trainer's Manual guides trainers through a course to support parents, guardians and carers affected by HIV and AIDS, by helping them to:

- share information, hopes and fears with their children
- strengthen each child's sense of identity and belonging
- plan for the future care of their children.

Many parents who have completed the course feel empowered to overcome the fear of disclosing their HIV status. This starts a process of breaking down 'walls of silence'. Experience shows that when children learn the truth about HIV and AIDS and can share in their family's problems, they start to face up to the future. Trusted with the truth, it is generally less frightening for them than if parents tell them very little, leaving them to worry alone.

## Who are the manual and course for?

The manual is written to support trainers with all levels of experience, but all will need some basic HIV and AIDS training and/or knowledge. It guides trainers through a course that is designed to be delivered to:

- parents and other family members living with HIV and AIDS
- future guardians of children affected by HIV and AIDS
- community workers and volunteers working with children and families affected by HIV and AIDS.

It can be delivered to people with varying levels of education, but the trainer will need to adapt it to suit the local cultural context and reality. All participants will have the common aim of wanting to prepare for their children's futures, safeguarding as far as possible their children's emotional, physical and financial wellbeing.

Because the course is relevant to an increasingly wide group of people involved in providing support to children, it is important for the trainer to note that not all participants will be living with HIV themselves.

The manual can also be adapted to train future trainers to deliver the course.

The manual draws significantly on the experiences and ideas of NACWOLA trainers and trainees, as well as those of Healthlink Worldwide and others. We see it as a living document that can be adapted and improved over time, informed by our growing experience.

## Aims

The aims of the course are to:

- improve understanding of child development and explore children's differing needs at different stages
- explore parenting styles and promote an understanding of positive relationships between parent and child
- explore issues of disclosing HIV status
- help parents prepare their children for the impact of separation and loss
- help parents, guardians and carers prepare and plan for their children's futures, and explore how children and teenagers can participate in these processes
- explore aspects of new family relationships
- improve understanding of the purpose and benefits of making a memory book

- explore how to make a memory book
- improve understanding of key legal issues involved in safeguarding children's futures
- help parents, guardians and carers plan a way to make the most of their learning after the end of the course.

## How to deliver the course

The course consists of 12 modules. Ideally you will be able to cover all the modules. However, the course has been designed to be flexible so that if there is not enough time, or you decide as a group that you do not need particular modules, it is possible to drop some of them. Module 1, the introductory session, guides you and your participants on how to prioritise and negotiate which modules to cover. Modules 1 and 12 are essential and should not be dropped.

As you go through the manual you will see that each module has a consistent structure, shown in the box below, to help you plan the session:

### Structure of the modules

#### Trainer's introduction

This includes:

- the approximate length of each module
- the aims of each session or module
- the key learning outcomes.

#### Trainer's preparation

- Module plan – this guides you on how much time to spend on each topic. These are suggested times only and can be adapted to your group's needs. Before each session, please add refreshment and meal breaks to the module plan that you show to the participants. These should be added at intervals that suit your course's circumstances.
- Materials you will need – this tells you what extra materials are required for the session. Use whatever materials are appropriate and available to you. These may include overheads, flipcharts or other presentation materials. For the purpose of this manual, we have marked certain sections for use on an overhead or a flipchart, but you can adapt this as necessary. Whichever method you use, please ensure that you prepare appropriately before the session.
- Trainer's notes – these are briefing notes for you for information and to help you plan the session. The notes are placed at the end of relevant modules but do not appear for every module. These notes are for you, the trainer, and should not be delivered directly to participants.

#### Trainer's guidance

Under this heading we have set out the content of the module that you will cover with participants. We offer guidance on how to tackle each topic and activity, and key points to bring out in discussion to help participants get the most from the course.

The modules are designed to give you some flexibility as you deliver them. We have given suggested times for each activity so that, if time is short, you can choose to focus on one or two activities that best meet the needs of your participants and leave the others out. Groups may need more or less time, depending on their levels of learning, experience and knowledge.

## Size of the group

We recommend that you deliver the course to groups of 12 to 16 participants. This is a good number to enable discussion and encourage everyone to take part.

## Length of the course

The full course is intended to run over seven to eight days. If, together with the group, you decide to leave out a module, you can change the timing of the course accordingly.

A field visit could also be included in the training workshop, for example, to an organisation carrying out memory work in the local area, or to a family that has been using the approach. Extra time needs to be allowed for this and as trainer you will need to make a preparatory visit before the course starts. You may also wish to add in an extra day for looking at the practical aspects of implementing memory work.

## The approach of the course

The course will best work for you and the participants if you encourage a **participative approach**. This means that you should encourage everyone in the group to actively participate and contribute to discussions and activities. Gently encourage them to reflect and share with each other their personal experience and knowledge and how they are affected by the different issues. Participants are more likely to be open if they feel they will not be judged, and will be listened to with respect. Encourage these attitudes in the group. Say that if participants want to challenge what a member of the group says, it must be clear they challenge the view and not the person.

Guidance on how to be a good trainer or facilitator is outlined in *Tips for Trainers* on page 10. Read it carefully. Note those points you already do and keep doing them. Recognise your areas for development and think about how you can improve on them for this course.

## Pre-planning

We recommend you plan well in advance. **Go through the manual weeks before the course starts**, to help you absorb and reflect on some of the issues and to arrange for support where necessary. You will need to make practical arrangements such as finding an appropriate venue, organising meals, copying handouts and getting flipcharts, an overhead projector and video player if available.

Think about the people you are preparing the course for. Consider how you can adapt some of the activities to make them fit the particular local context. Can you do anything to make the content and activities more relevant and stimulating for your group? Consider the difficulties and challenges that might arise among the group you will be working with and how you would address them.

The more time you spend preparing for the course, and refreshing your memory about each module the day before you deliver it, the more confident you will feel, and the more you will encourage participants to take part and get the most from the course.

## Practical preparation for the course

The materials and equipment you will need for every module are:

- flipchart, marker pens and sticky tack or drawing pins
- overhead projector, screen and transparencies or flipchart paper or any other appropriate material available to you. You will find the content of overheads/flipcharts clearly marked in each module
- pens for participants.

Extra materials or equipment you will need are listed under the **Trainer's preparation** heading in the modules.

Prepare name badges for the participants and yourself, and ensure that all participants know where to find facilities such as the toilets.

### Complementary resources

Some key resources complement the manual to help you deliver the course effectively. These include:

- *The Memory Book for Africa* (revised ed 2000), which includes guidance on how to use and make a memory book and a memory basket, and is available in a range of African languages.
- *NACWOLA Guide to Legal Information for Parents Living with HIV/AIDS in Uganda*, which gives guidance that can be adapted to the circumstances of different countries. Topics include legal protection for children, writing a will and securing property rights, all of which are vital parts of memory work.
- **Videos**, including some or all of the following:
  - Everyone's Child* (Media for Development Trust, Zimbabwe, 1996, colour, English, 85 mins): to support Module 6
  - Beyond Survival* (TILLA – Association of Women Living with HIV, Ethiopia, 1997, colour, 25 mins): to support Module 5
  - A River of Hope* (Healthlink Worldwide et al, 2003, colour, English, 44 mins): To support Module 10
  - Neria* (Media for Development Trust, Zimbabwe, 1990, English, Portuguese and Swahili, 103 mins): to support Module 11.

Please see Appendix 1: Key course materials (page 123) for more information.

### Emotional content and demands on the trainer

The nature of the course presents you with some particular challenges. Many of the issues you will cover are complex and can be difficult to talk about. You are likely to address family relationships, parent-child relationships and sexual relationships and practices. These areas are sensitive at the best of times and will be particularly so during the course.

You need to be aware of your own feelings and the feelings in the group. Be prepared to take a break if people get too upset and tell participants it is fine to leave the session for a while if they need to. Make sure there is a place where participants can go if they become very emotional. If possible, arrange for someone who can listen to them.

Although honesty and openness are encouraged throughout the course, it is important not to force this on participants. The most you can expect is for people to be ready to ask themselves difficult questions about their own attitudes and behaviour, and those of the important people in their lives.



## Tips for trainers

If you already do all the things on the list, you are a wonderful trainer. Most of us do some of these things, but not all of them. Tick those points you already do and keep doing them. Think carefully about the points you do not do yet and prioritise the ones you think you can start to do most easily. You will find you can tick more as you gain experience.

### Prepare well for the course

- Be well organised and plan in advance. This includes practicalities like photocopying handouts, preparing overheads and flipcharts (or other presentation aids you are using), checking all equipment, having all supporting resources and facilities ready on time, checking the suitability of the venue, and arranging appropriate meal and break times and menus.
- Always plan to arrive at the venue well before the participants to ensure the room is ready and to sort out any problems so you can start the session on time.
- Use this manual flexibly and adapt it to fit local circumstances and the needs of the particular group. Each group will be different.

### Be participative

- Be a good listener and respond to the needs that participants express.
- Be sensitive to the needs and emotions of individuals and groups.
- Make all participants feel safe, respected and valued.
- Encourage everyone to take part. Give quiet people a chance to speak. Tell people who speak too much that the group need to hear other people's thoughts too.
- Motivate and inspire people.
- Ask people to help when appropriate.

### Help people to get the most from the course content

- Provide guidance and leadership. For example, make sure the agreed content of modules is followed. This will only happen if you keep time effectively and move people on when necessary.
- Be flexible, so that you can include important issues as they arise, while recognising the importance of keeping to the timetable.
- Know the course well so you can link: activities to learning points; topics to people's individual needs; and themes between sessions.
- Draw out the important points from participants' contributions and summarise them to the group.
- Be thought-provoking and challenge people to think.
- Admit when you do not know something. Participants will generally appreciate your honesty.
- Be ready to tell participants where they can get help and support after the course ends.

### Deal with differences

- Appreciate that participants have had a range of experiences and are likely to be at different starting points. Their levels of engagement and the pace at which they move will also differ. Be ready to explain things more than once and to summarise points.
- Be prepared to manage tensions and conflict, for example, by making clear what is and is not relevant and appropriate to the course. Ask individuals to sort out their differences at another time if necessary.

**Good luck!**

## Key words and phrases used in the manual

As you go through the manual you will see words and phrases that might be unfamiliar or need clarifying. Here is a list of key words and phrases to help you.

### 1. Related to training

**Befriender:** a person who acts as a friend or helper.

**Brainstorming:** to share everything that comes to people's mind about an issue or topic.

**Communication:** the two-way giving and receiving of information and ideas.

**Pair:** group of two people.

**Participant:** someone who actively takes part or joins in.

**Participative (or participatory):** describes an approach that encourages everyone to actively take part or join in.

**Small group:** a group of three or four people.

### 2. Related to memory work

**Disclosure:** revealing private information or the truth about a secret.

**Family tree:** a diagram that shows how people are related and from whom they are descended.

**Memory book:** a written record of family and individual history, important facts, memories, hopes and messages. They can be written by parents or guardians with or for children, or they can be written by children themselves.

**Memory work:** Memory work is a community-led approach to communicating about HIV in the family. It addresses a variety of issues including:

- improving communication between guardians and parents living with HIV and their children
- disclosing HIV status
- imparting other important information
- planning for legal guardianship and inheritance (succession planning)
- writing important family history in a memory book.

A variety of activities take place around these main pillars.

**NACWOLA:** National Community of Women Living with HIV and AIDS in Uganda.

**People affected by HIV and AIDS:** includes PLHA (see below) as well as people not living with HIV or AIDS themselves, but who are otherwise affected by their impacts.

**PLHA:** People living with HIV and AIDS.

**Role-play:** to act out real-life situations, playing the role of certain characters.