

## MODULE 5

# Disclosing HIV status



### Trainer's introduction

This module looks at helping people to disclose (tell others about) their HIV status. It guides participants who are personally affected by HIV and AIDS to prepare for disclosure and to decide who needs to know their status. The focus is on parents/guardians telling children but it will help participants to reveal their HIV status and other sensitive issues to adults too.

Remember that some participants may not be living with HIV themselves. This module will help them understand how children might be told about their parent's, guardian's or friend's HIV status. These participants will then be in a position to give support to the child.

Approximate length of module 3 hours 25 minutes to 3 hours 45 minutes

### Aims

The aims of this module are to:

- provide an understanding of what HIV disclosure means
- explore the implications of deciding to disclose or not to disclose HIV status
- help participants prepare for disclosure of HIV status and other sensitive issues.

### Key learning outcomes

By the end of this session participants will:

- have an understanding of what HIV disclosure means
- have an understanding of the implications of disclosing or not disclosing HIV status
- have prepared for, and practised, disclosing HIV status
- have an awareness of the impact of disclosure upon others.

### Trainer's preparation

#### Module plan (with suggested times)

- Looking at what disclosure means and who needs to know – **1 hour 10 minutes**
- Understanding the implications of disclosing or not disclosing HIV status – **40 minutes**
- Preparing for disclosure of HIV status and other sensitive issues – **1 hour 15 minutes to 1 hour 35 minutes**
- Reflection – **10 minutes**



#### Materials you will need

Overhead/flipchart 1: Outline of Module 5

Overhead/flipchart 2: Who needs to know?

Overhead/flipchart 3: Difficult and easy people to tell

Handout 1: Difficult and easy people to tell

Handout 2: Some key points about disclosing to children

Handout 3: Disclosure role-plays

Video: *Beyond Survival* (optional) see Appendix 1: Key course materials, page 123

TV & video player

## Trainer's notes

Please make sure you read the trainer's notes at the end of this module (page 53). They give you useful background on HIV disclosure issues and ways to prepare for disclosure.

## Trainer's guidance

### Introduction

Before you start the session, be aware that this module may touch upon some vulnerable feelings in the group. You will need to be sensitive to how participants are reacting. Do not force anyone to disclose information. This is a personal decision for each individual. This point is very important, because of the possible consequences of disclosure. Please also remember that you should not assume that all participants are living with HIV; the module can also guide participants to address disclosure issues in the communities where they will be implementing memory work.

Start by explaining that the purpose of this module is to explore aspects of disclosing HIV status. Say that together you will look at what disclosure means, who needs to be told and how to prepare to tell people. Explain that the focus will be on how to tell children in an appropriate and sensitive way, but what participants learn in the session can be used for disclosing to adults too. Emphasise that **no one will be forced or persuaded to give information about themselves** in the session. Remind all participants about the group agreement and stress the importance of confidentiality.

Go through the topics to be covered in the module and how it is structured.

### Overhead/flipchart 1: Outline of Module 5

Please use the list in the module plan on page 41, but without the suggested times.

## Looking at what disclosure means and who needs to know

Start by explaining that disclosure means being open and revealing the truth about a secret. Say that in this training course when we speak about disclosing we are talking about something very personal and sensitive. In the context of this group, it means talking openly about HIV and AIDS in the family. Encourage participants to think of disclosure as ongoing, rather than a single act of communication with another person or child.

Also say that disclosure can happen accidentally, for example, if a child overhears an adult conversation. When disclosure happens this way, the message has not been prepared appropriately for the child. This might cause worry and distress. Say that whenever possible, it is important to manage disclosure carefully and sensitively.

### Activity 1 Exploring who needs to know about a person's HIV status

**Suggested time: 35 minutes**

Explain that the aim of this activity is to explore who needs to know about a person's HIV status.

1. Divide the participants into three groups. Tell them they will have 15 minutes to discuss the questions on the following overhead/flipchart, after which one person from each group will feed back to the whole group.

**Overhead/flipchart 2: Who needs to know?**

- Who needs to know about HIV and AIDS in the family?
- What do different people need to know?
- How do you think family and friends will react?
- How will it affect employment, relationships (especially marriage) and social life?

2. Bring everyone back to the whole group. Give each group representative five minutes to report the main points of their discussion. Ask the group for comments and questions.

3. Summarise the main points of the discussion and make sure the following points are brought out:

- There are some people who need to know about HIV and AIDS in the family: for example, the children of the person disclosing. But the person disclosing does not have to disclose to everyone.
- When a person does disclose her or his status to someone, she or he does not have to tell that person everything related to it.
- If a person chooses not to tell certain people, she or he may need to be prepared to answer awkward questions. This may also be the case when people find out a person's HIV status another way.

### Activity 2 Deciding who needs to know and how easy or difficult it will be to tell them

#### Suggested time: 30 minutes

Before you start this activity please note that it could be very painful and upsetting for some participants. Emphasise that it is designed to help participants to think about the issues together and to learn from each other. Make it clear that if anyone does not wish to discuss their personal situation in the group, they do not have to. Say some individuals may wish to think about their own situation elsewhere or with support, for example, with a counsellor.

If participants living with HIV feel uncomfortable doing the activity with people who are not, you could ask the participants not living with HIV to form their own group and *imagine* who they would need to tell and the difficulties involved. Alternatively, you could mix the groups let the participants support each other, whatever their HIV status.

Encourage everyone to participate as far as they want to. This might be simply listening to others in the group talking about how they have faced similar challenges to their own.

Explain that the aim of this activity is to help each person consider who needs to know about their HIV status and who will be easy or difficult to tell.

1. Divide participants into groups of three. At least one person in each group needs to be able to write. Tell them they will not share what they write with the whole group. They will discuss only in the small groups for this activity.
2. Give them 10 minutes to discuss and make a list of all the people (children and adults) they need to tell about their HIV status.
3. Display overhead/flipchart 3 – *Difficult and easy people to tell* (see page 44) and give each participant a copy of Handout 1, which contains the same chart (see page 50).
4. Ask the participants to put the names of people on their list into the appropriate squares. Provide some examples like the following: Auntie Jean might fit in the 'difficult, but less important to tell' box, sister Anna might go in the 'easy and important to tell' box, son Ahmed might go in the 'difficult and important to tell' box.

As you say these names write them in the squares on the overhead/flipchart and give

some examples of why each person might be easy or difficult to tell. For example, Auntie Jean might not be very good at listening. Sister Anna might be a sympathetic person who gives good advice. Son Ahmed might be someone you need to prepare carefully to tell – you might need to practise with a supportive adult beforehand.

Give the group 10 minutes to fill in their boxes.

**Overhead/flipchart 3: Difficult and easy people to tell**

<b>Difficult and important to tell</b>	<b>Easy and important to tell</b>
<b>Difficult, but less important to tell</b>	<b>Easy, but less important to tell</b>

5. Ask each small group to discuss the following questions among themselves, with each person taking five minutes:

- What makes it hard for you to talk to the people in the ‘difficult and important’ box?
- Who is it difficult for – the people in the box or the person doing the telling?
- What might make talking to these people easier?
- Where or whom might you get support from?

Say that as each person talks, the people listening should not give the speaker their opinion of what to do. Instead, they should ask encouraging questions to help the speaker think about it. For example: “Tell me more...”, “Can you explain that some more...”, “What else could you do?”

6. Finally, ask participants to help each other in their groups to plan how they can use the people in the ‘easy and important’ box to help them to talk to the people in the ‘difficult and important’ box. Allow five minutes for this.

## Understanding the implications of disclosing or not disclosing HIV status

Introduce this topic by explaining that it is important to realise that whether a person chooses to disclose his or her HIV status or not, the decision will have consequences. The following activity will help the group to examine what the positive and negative effects of the decision might be.

### Activity 3 Exploring the possible consequences of disclosing HIV status to children and other family members

**Suggested time: 40 minutes**

Explain that the aim of this activity is to explore the possible consequences of disclosing HIV status to children and other family members. The activity also explores sources of support for the person disclosing.

Please note that, depending upon the priorities of the group, you may wish to focus just on children or to consider families as a whole.

1. Ask participants to divide themselves into four small groups.
2. Ask two groups to think about the possible advantages of a person disclosing their HIV status to her or his children and family. Ask the other two groups to think about the possible disadvantages. Give them 10 minutes to do this.
3. After their discussions, ask all the groups to take five minutes to consider sources of coping and support that might be available to them. Ask them to have one person from each group to be ready to give feedback.
4. Bring the groups back together and ask the volunteers from each group to feed back some of the points that came out of their discussions, taking two minutes each.
5. Finally, ask for comments from the whole group. Summarise the main points and make sure the following points are covered:

#### **Some advantages of disclosing:**

##### **To adults**

- There is no worry about being found out and having to keep up pretence.
- It is easier to get medical treatment and support.
- It is easier to negotiate safe sex.

##### **To children**

- Being open helps parents and children to support and trust each other.
- Children will be less vulnerable to being hurt by rumours from outsiders.
- It makes it possible to plan for children's future in good time and the children can take part in planning for their own futures.
- Parents find that after they have faced this issue with their children, they are free to talk about many other things. They usually start listening to and understanding each other better.
- Children have time to ask questions, and find out about their family and background.
- Older children can begin to take on family responsibilities.
- Although children cannot be protected from the pain of losing a parent, they are better prepared and the shock will be less.

#### **Some disadvantages of *not* disclosing:**

##### **To adults**

- It often involves being untruthful, which can be stressful.
- Awkward questions may need to be answered.
- The person might be afraid of being seen at clinics and AIDS support centres, and may miss the treatment and the support he or she needs.

- It is harder to negotiate safe sex.

#### To children

- It makes it very difficult to prepare children for the loss and change they will have to face.
- Children might feel disgrace and stigma. This can lead to low confidence.
- Children cannot be involved in making plans they agree with.
- It will not be so easy to pass on important information and skills to children.

Highlight any good ideas that participants contribute for sources of support. Make a distinction between emotional support from friends and family, and practical support, for example, from clinics and AIDS support centres. Stress that if someone decides to disclose their HIV status, they will need support and should think about where to find this before they disclose.

At this point you could read out the following words from NACWOLA mothers in Pallisa, Uganda:

“Under the memory project, I got the strength for telling my children my status.”

“I would advise other mothers to disclose their status. This gives confidence and people can then associate with others. It removes their fear and clears stigma. It opens you to other people.”

## Preparing for disclosure of HIV status and other sensitive issues

Please be aware of how participants are reacting and allow people to leave the room if they need to. Explain to participants that after a person has made the decision to disclose, it is important to prepare how to do it. The activities will help the group think about preparation and give them an opportunity to practise, through role-plays, how they could approach disclosure and how they might answer questions.

### Activity 4 Exploring how to tell a child that a parent is living with HIV

#### Suggested time: 40 minutes

Explain that the aim of this activity is to explore how to tell a child or children that a parent is living with HIV.

1. Ask participants to divide themselves into small groups, according to the age of their children or a child they want to focus on. For example, groups could consider children in the following age ranges: 4-6; 7-12; 13-18.
2. Ask each group to discuss how to disclose HIV status to children of the age group they have selected. What factors would they need to consider? Which words would be appropriate to use? Tell them they have 15 minutes, after which you will ask for volunteers from each group to feed back.
3. Bring everyone back to the whole group and ask for the feedback. Be prepared for participants to be upset and unable to say very much. Allow five minutes for all the feedback.

Next, make the presentation on the following page. It contains key information, so make sure you have prepared it well.

## Presentation

### Some key points for a person disclosing HIV status to children

#### Preparing

- Be clear about what you want to say and what the child needs to know.
- Break this down into smaller pieces that can be given to the child one at a time. For children aged four to six, it helps to put the information in the form of a story. For older children who can read, you could prepare a letter to start the process. The child can read it at a quiet time and think about it before you speak together.
- Make sure the information you give is appropriate to the child's level of understanding.
- Practise what you want to say with an adult you can trust before you disclose.
- Think about the signs your child shows when they are upset and be ready to stop if you see these signs. Some children feel more comfortable talking to another adult outside the immediate family. This might – but not always – be true for children between the ages of 7 and 12, who often admire other adults in their lives such as uncles, aunts and teachers. You will need to be able to trust and feel comfortable with such a person before you share this responsibility with them.
- Think of the questions they might ask and think through your possible answers.
- It helps if you have already started thinking about plans for the future so you can reassure your children they will not be left alone.
- When you know what you want to say, be ready for the right time to say it: for example, when your child raises the subject of illness or has AIDS lessons at school. Make sure both you and the child are calm and that you will not be interrupted before you begin.

#### Telling

- Decide what to begin with and do not talk for too long.
- Be clear and ready to summarise the important points.
- Be honest and calm.
- One way to start is to talk about illness generally, then about your own personal illness, and then HIV and AIDS in the family.
- Stop if your child shows signs of distress, becomes quiet, looks away or changes the subject. Comfort the child.
- Be ready to answer questions like: “How did you get it?”, “Have I got it?” and “When will you die?”
- Be ready for shock, anger, blame and denial. Remember, these reactions will pass with time.

Give participants *Handout 2*, page 51.

Next, you could read out the following story. It is a real example of how a mother told her son about her HIV status and the negative and positive effects the disclosure had.

Carla had attended a Memory Project training. Afterwards she decided to disclose her status to her 19-year-old son. She started by teaching her son about the facts, myths and misconceptions about HIV and AIDS. Then she took him out and after spending a wonderful day together she said: “There is something that has been bothering me and I did not know how to tell you. I am HIV positive...” The boy was extremely shocked. Soon after, his school grades began to drop and he isolated himself.

The boy was given counselling and with time he accepted the situation. He has now become supportive and has joined a youth group that uses theatre and music to sensitise the community on HIV and AIDS.

You could then read out the words of a Ugandan lady who describes how she disclosed her status to her older daughter:

“I used the techniques I acquired from NACWOLA and initiated a conversation with my elder daughter one evening at home. I cracked a joke about death and gave options of types of death, for example, an accident or HIV, for her to choose if it were possible for one to make a choice. She suggested HIV, because she urged that according to the knowledge she got from her school, someone with HIV could stay alive for many years until it developed into AIDS, unlike an accident. My daughter’s response gave me an entry point to disclose my HIV status.

“Following on from this conversation, I said: ‘My daughter, do you remember my conversation and jokes about the options of death we talked about?’ My daughter answered in a relaxed mood: ‘Yes.’ I then told her: ‘I have HIV!’ She responded: ‘Mama nga tulabye!’, meaning ‘Mummy, it is a pity to us!’ I saw her emotionally touched, but I tried to comfort and counsel her. Since then she has taken the responsibility for me and her sisters. She has become supportive and I equally feel relieved.”

Close this activity by saying that the person disclosing must be ready to deal with the effect of what is said upon the child and to be loving and supportive. The person disclosing will also need emotional support.

### Activity 5 Disclosure role-plays

**Suggested time: 30 to 50 minutes**

See the note below about preparing your own role-play situations based on the specific needs of the group. If you decide to do this, you will need to prepare well before you do this module.

Explain that the aim of this exercise is to give every participant the chance to ask and answer difficult questions about HIV disclosure. Say that this will be done through role-plays in small groups. Reassure participants they will not have to perform role-plays in front of the whole group.

1. Divide participants into small groups of three people. Say that each group will be given a situation with a mother and child talking. Ask participants to decide who in each group will take the roles of the mother and child and who will be the observer. Make sure each group has enough space to work without disturbing the others.
2. Give each group a role-play handout (see below). If there are more than four groups you can give the same role-play to more than one group.
3. Give the groups three minutes to read the information on their handout and tell them they have five minutes for their role-play. Encourage participants to use what they learned from the previous activity to guide how they disclose in the role-play.

### Sample role-plays

Four sample role-plays, which are based on NACWOLA training and experiences, are presented in Handout 3, page 52. All except one are scenarios involving a mother and a child. It would help your group to learn if you could develop other role-plays, based on what you have heard in the stories of your participants. If you decide to do this, you must get permission from people to use their stories in this way (without names, so other participants and groups do not know which story belongs to which person).

4. At the end of the role-plays, give participants 10 minutes to discuss the following questions in their groups:

- What happened during the role-play?
- Was it realistic?
- What feelings came to the surface?
- What have you learned from the experience?
- How could you use the experience in your own situation?

5. Bring everyone back together to share ideas and highlight key learning points. Ask the people playing the role of mother whether they remembered to use some of the learning points from the previous activity and if so, which they found most useful. If they forgot to do this, ask them to think now about which ones they could have used. Allow 10 minutes for this.

6. If you have enough time, repeat the role-playing until everyone has had a chance to experience being the mother, the child and the observer. You can use the same role-play or change it each time. Remember to build in the extra time for doing this.

7. At the end of the discussion, ask everyone to leave their roles behind, by saying their own name and that they are not the character they were role-playing.

## Reflection

### Activity 6 Reflecting on the module

**Suggested time: 10 minutes**

Tell participants that the module is coming to a close and that this activity provides an opportunity to share any anxieties and key learning points in an informal way. Say that this is a way to unwind after what has been an intense session at times.

1. Tell the group that you are going to ask them to walk around the room or the compound, at a speed that is comfortable for them. Every now and then you will ask them to stop and have a chat with a friend.
2. Ask participants to move any chairs or mats to the edge of the room.
3. Ask participants to walk slowly, this way and that, until you call out: “Stop!”
4. When you call “Stop!” ask them to stand still, look around and find someone they would like to talk to. Ask them to make their way to that person or group of people.
5. Ask participants to talk to each other about the session. What do they feel about it? What were the most important issues for them? What did they learn?
6. After two minutes, tell them all to walk on again. They can walk on alone or with the person they have been talking to.
7. Ask them to stop again and repeat the process until everyone has talked to at least two other people.

Bring the module to a close. Thank participants for their contributions and for being open about these difficult issues. Say that you are looking forward to seeing them at the next session.



## Handout 1: Difficult and easy people to tell

<b>Difficult and important to tell</b>	<b>Easy and important to tell</b>
<b>Difficult, but less important to tell</b>	<b>Easy, but less important to tell</b>



## Handout 2: Some key points about disclosing to children

### Preparing

- Be clear about what you want to say and what the child needs to know.
- Break this down into smaller pieces that can be given to the child one at a time. For children aged four to six, it helps to put the information in the form of a story. For older children who can read, you could prepare a letter to start the process. The child can read it at a quiet time and think about it before you speak together.
- Make sure the information you give is appropriate to the child's level of understanding.
- Practise what you want to say with an adult you can trust before you disclose.
- Think about the signs your child shows when they are upset and be ready to stop if you see these signs. Some children feel more comfortable talking to another adult outside the immediate family. This might – but not always – be true for children between the ages of 7 and 12, who often admire other adults in their lives such as uncles, aunts and teachers. You will need to be able to trust and feel comfortable with such a person before you share this responsibility with them.
- Think of the questions they might ask and think through your possible answers.
- It helps if you have already started thinking about plans for the future, so you can reassure your children they will not be left alone.
- When you know what you want to say, be ready for the right time to say it: for example, when your child raises the subject of illness or has AIDS lessons at school. Make sure both you and the child are calm and that you will not be interrupted before you begin.

### Telling

- Decide what to begin with and do not talk for too long.
- Be clear and ready to summarise the important points.
- Be honest and calm.
- One way to start is to talk about illness generally, then about your own personal illness, and then HIV and AIDS in the family.
- Stop if your child shows signs of distress, becomes quiet, looks away or changes the subject. Comfort the child.
- Be ready to answer questions like: “How did you get it?”, “Have I got it?” and “When will you die?”
- Be ready for shock, anger, blame and denial. Remember, these reactions will pass with time.



## Handout 3: Disclosure role-plays

### Role-play 1

**MOTHER:** You are a widow, 45 years old and you have two teenage sons. You have been very tired and ill in recent weeks. Just when you need more help, your younger boy, aged 14, has become very quiet and spends a lot of time away from home.

**SON:** You are not sure what is going on at home. You feel you cannot ask questions and it is easier to stay out of the way with your friends. One day your mother looks really ill and you burst out with the question: "What exactly is wrong with you, mum?"

**Mother:** What do you say?

**Son:** How do you react?

### Role-play 2

**MOTHER:** You have four children aged 13, 12, 9 and 6 years. Your two sisters have come round, because they know you are not well. Your young sister has taken the children into the compound, leaving you alone with your older sister. You want to ask for help but you don't know how to start.

**MOTHER'S OLDER SISTER:** You have guessed your sister is HIV positive and you think it is time she told her two older children.

**Mother:** How can you let your sister know you need help?

**Sister:** How can you raise the subject?

### Role-play 3

**MOTHER:** Your husband recently died. You know he had AIDS, but so far you have managed to keep this secret from your relations and your children who are aged 15, 7 and 3. But now you have heard there are rumours going round the neighbourhood.

**OLDEST CHILD:** When you went back to school after the funeral, people were staring at you and you felt they were talking behind your back. You guess it is about your father, but your mother keeps avoiding the subject.

**Mother:** What do you want to tell your children? What do you need to do and say?

**Oldest child:** What do you want to ask your mother?

### Role-play 4

**MOTHER:** You have been getting more and more tired. Cooking, cleaning and fetching water are too much for you to manage on your own. You want your eldest daughter, aged 16, to organise the other five children to share the work. You have not disclosed your status to your daughter, because she is at the stage of being a difficult teenager.

**OLDEST DAUGHTER:** You feel your mother is expecting too much from you, but she doesn't treat you as an equal. So why should you take responsibility for getting the younger children to help out?

**Mother:** What can you do to get your daughter on your side?

**Daughter:** What do you want your mother to say or do?

# MODULE 5 – Trainer's notes

## Guidance on disclosure of HIV status

These notes will help you understand the issues and deliver the module effectively. In particular they support activities 3 and 4. Please read the notes carefully so you can offer additional learning points and facilitate discussion with the group throughout the module.

You may wish to use the video *Beyond Survival* at the beginning of this module to aid discussion (see Appendix 1: Key course materials on page 123).

### Disclosure

Many parents have already struggled to disclose their HIV status to their children, families and communities. Some were the first people in their community to speak out about their HIV status. They have given courage to other parents to do the same and talk openly to their children. Many NACWOLA women say that when they work out how to say the words, a weight is lifted and they feel freer to get on with their lives.

### Why disclose?

Many people try to keep their HIV status hidden, because they are afraid of what will happen to them or their family if the truth comes out. However, when people hide their HIV status it can cause many problems:

- It takes a lot of mental energy, always being worried about being found out, waiting for awkward questions.
- It often involves being untruthful, which over time can cause problems.
- It makes it difficult to get medical treatment or support, for fear of being seen in a clinic or AIDS support centre.
- It makes it impossible to prepare children for the loss and changes they will have to face.
- It makes it harder to negotiate safe sex.

### Talking to children

The notes below are adapted from Gerard Egan's book *The Skilled Helper* (1997/2001). This book was written to support professional staff working with families and individuals facing loss, separation or other major life changes. We have also added experiences and ideas from NACWOLA women.

For many parents, disclosing to their family is one of the worst things they face in relation to their HIV status. Unfortunately, because of the shortage of health workers, counsellors and other skilled helpers, most parents have to manage on their own. But if possible, it is important that people are assisted to prepare for this challenge. Knowing something about the different stages of disclosure and the skills required will help parents get started and stay on track.

#### 1. Preparation: 'Preparing the ground'

Just as the ground has to be prepared before planting crops, parents and carers must prepare for the time when they will speak to their children about their HIV status. They will need to think about:

- WHY they need to talk to their child/children
- WHAT they need to tell their child/children
- WHERE they can talk with their child/children

- WHEN is the best time to talk to their child/children – there will never be a perfect time for this, just a time that is good enough.

**Good reasons for disclosing to children, according to NACWOLA women:**

- Being open helps parents and children to support and trust each other.
- Children get correct information directly from their parents.
- Children are less vulnerable to being hurt by rumours from outsiders.
- It makes it possible to plan for the children in good time.
- Children can be involved in making plans they agree with.
- Parents find that after they have faced this issue with their children, they are free to talk about many other things. They usually begin listening to, and understanding, each other better.
- Parents have time to pass on important information and skills to their children.
- Children have time to ask questions, find out about their family and their background.
- Older children can begin to take on family responsibilities.
- Although children cannot be protected from the pain of losing a parent, they are better prepared and the shock is less.

**Talking to children who do not want to listen – tips from NACWOLA women:**

There is never a perfect time for a parent to talk to her or his children about HIV in the family and some children will resist. This can make an already difficult and painful task even harder. Depending on the ages of the children, the suggestions below might help:

- Be clear about what you need to say.
- Break it down into small pieces of information that can be given to the child one at a time.
- Decide what to start with. Do not talk for too long.
- Make sure the information is appropriate to the child's level of understanding.
- Decide how to tell essential sensitive information to those individuals who really need to know it. For example, this could be by leaving written information for each child that includes facts important for that child (for instance, about the child's father). Or you could write a letter to go with the memory book, to be held by a trusted friend until the child is older.
- If the child is young, it may help to put the pieces of information into a story.
- If the child is older and can read, it might help to start with a letter. This gives the child the opportunity to read and digest the information at a quiet time.
- If older children in the family know about the situation, they might be able to help tell younger children.
- Sometimes a child will feel more comfortable talking to another adult, someone outside the immediate family.
- Watch the child's body language as you speak. Be ready to stop if the child has had enough.

## **2. Telling children**

Egan (1997/2001) describes three steps that parents or helpers need to take. These steps are given below with notes to outline the skills and attitudes required by parents or helpers who plan to talk to children about HIV and AIDS in the family.

### **Step 1: Exploring (telling the story)**

At this stage, the parent or carer will tell his or her story, talk about the problem and what is on his or her mind. He or she tells it in his or her own way and own time.

To tell the situation as it is, the parent will need to be:

- clear – able to explain in words that the children will understand
- honest – not afraid to say difficult things
- aware of good timing – know the right moment to begin, go slowly enough for the children to take in the information, and give them a chance to check what they do not understand
- calm – this helps the children not to panic when they receive information
- child-centred – keep to what the children need to know. Do not give unnecessary detail or blame others
- understanding – be aware of how the children are feeling and give them comfort or a break to recover from immediate shock or distress
- supported – is there a reliable friend or relative who could support you to tell the story? Or is there someone who could give comfort and practical support? For example, he or she could prepare food while the family discusses their situation.
- focused – be able to summarise the most important points
- patient – be ready to go over the story as many times as necessary.

### **Step 2: Understanding (options and alternatives)**

At this stage the parent or carer tries to make it easy for the children to ask questions. The children need to be able to ask how this problem might affect them and what they can do about it. This could be a family brainstorming session. Everyone could be allowed to ask and say whatever they think, no matter how impossible or difficult their questions and ideas might be.

To give the children a chance to question and come up with ideas, the parent or helper will also need to:

- listen – hear and react to what the children have to say
- reflect back – make sure the children know their ideas and fears have been heard – for example, you could say: “Let me get this right, what you are saying is...”
- ask the right questions – help the children be clear about what they are trying to say
- challenge – to not let false ideas or hurtful comments slip by
- encourage discussion – make it easy for all the children to join in with their ideas
- build on ideas – let children see that their views are respected and their suggestions can become part of the solution.

### **How to start talking to children: some ideas from NACWOLA women**

- Talk first to a reliable friend or relative, and practise saying the words.
- Discuss with this friend when and how you can start to talk to your children.
- Listen to your children and find out what they already know about HIV and AIDS.
- Watch out for ‘entry points’ that you can build on, for example, times when your child raises the subject of illness, AIDS lessons at school, radio programmes and so on. You may be surprised at how much they already know.
- Do not overload children with too much information and in general do not tell the whole story at one time. This will be too much for most children.
- It is better to start slowly, talk about sickness generally and build up to your own personal health and, finally, to HIV and AIDS in the family.
- Pick a quiet time to talk, without strangers in the house or possible interruptions.
- Give simple and appropriate answers, using simple, everyday language.
- Choose a time when your own health is okay and when you feel calm.
- Be prepared for shock, anger, blame and denial (these reactions will pass with time).
- You might find your children have already guessed. They might be relieved to hear the truth from you.

- Be ready to answer awkward questions like: “How did you get it?”, “Have I got it?”, “When will you die?”
- It helps if you have already started to make plans for the future, so you can reassure your children they will not be left alone.
- Be prepared to have this discussion many times. Children will absorb the information bit by bit. They will come back for more detail as they come to terms with the facts.

### **Step 3: Taking action (planning)**

At this stage the parent (or carer) and children need to slow down and think about the situation. Together, wherever possible, they will consider different possibilities and work out the best plan in the circumstances.

The plan needs to be:

- realistic – something possible to achieve, which will meet agreed needs
- manageable – not too complicated and only involving people who will definitely be able to help when the time comes
- ready in time – in place before a crisis happens
- achievable – even if the plan does not cover everything, the people concerned need to feel secure that what has been arranged will work.

To come up with useful plans, parents or carers will need to:

- be realistic – do not raise hopes of a perfect solution which does not exist
- be strong – help the children accept what is happening
- be firm – set time limits to work towards a good plan
- be fair – take everyone's fears and wishes into account
- keep going – reach decisions while there is still time to put plans into action
- involve and update the children at all stages.