

## MODULE 6

# Helping children cope with separation, loss and grief



### Trainer's introduction

This module looks at supportive ways in which parents can talk to their children about separation and loss, and prepare them to cope. It gives guidance on how to help relieve children's grief, and helps guardians and other carers to communicate sensitively when talking about these important topics with children. Here we build on Module 5 by developing the idea of the importance of planning communication.

Approximate length of module: 2 hours 30 minutes (up to 3 hours 40 minutes including the video)

### Aims

The aims of this module are to:

- provide an understanding of the impact of separation and loss
- help participants prepare children and others for separation and loss
- help participants understand the importance of planning for separation and loss.

### Key learning outcomes

By the end of this session participants will:

- have an understanding of separation and loss
- have explored death and dying
- have an increased understanding of children's fears of death
- have looked at ways to prepare children to cope with separation and loss, and have recognised the importance of planning.

### Trainer's preparation

#### Module plan (with suggested times)

- Understanding separation and loss – **45 minutes**
- Exploring death and dying – **40 minutes**
- Looking at children's fears of death and ways of preparing them to cope with separation and loss – **45 minutes or up to 2 hours including the video**
- Reflection – **15 minutes**



#### Materials you will need

Video: *Everyone's Child* (85 mins), if available – see Appendix 1: Key course materials (page 123).

TV & video player

Overhead/flipchart 1: Outline of Module 6

Overhead/flipchart 2: Exploring the death of someone important to you

## Trainer's guidance

### Introduction

Please note that this session deals with very emotional issues. It might be necessary to take extra short breaks between activities.

Explain that the purpose of this module is to explore separation and loss. Say that together you will look at the meaning of separation and loss, the impact of death and dying, and ways to plan and prepare children to cope. Remind the group that we have all survived separation and loss and these experiences will help us think about this subject, whether we are living with HIV or not. Ask participants to support each other through the module. Say that if any participants have recently experienced a death, it is fine for them to observe quietly and join in wherever they feel able.

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

#### Overhead/flipchart 1: Outline of Module 6

Please use the list in the module plan on page 57, but without the suggested times.

## Understanding separation and loss

### Activity 1 What do separation and loss mean to you?

Suggested time: 20 minutes

Explain that in this activity participants will look at what separation and loss mean to them. By looking at different views from the group this can help increase our awareness of the different ways that people are affected by separation and loss.

1. Ask participants to brainstorm the difference between separation and loss. Record their responses on a flipchart. Allow five minutes for this.
  2. Summarise the main points of the brainstorm. If participants have not made any distinction, explain that:
    - **Separation can be long or short.** For example: when a husband goes away to work for part of the year; when the children are sent to stay with a friend or relative, because their mother is ill.
    - **Loss means forever.** A phase of your life is over, for example, when you leave school or when someone important to you dies.
- Allow five minutes for summary and discussion.
3. Next, brainstorm with the group what separation and loss mean to them. Record their responses on the flipchart. Take five minutes to do this.
  4. Summarise the main points of the brainstorm. Make sure you bring out the following:
    - **Separation** generally leads to anxiety about what is going to happen, a mixture of hopes and fears.
    - **Loss** means the change is final. Thoughts and feelings might include shock, confusion, denial, hurt, loneliness, hopelessness, guilt, anxiety, anger and feelings of "why me?"

Allow five minutes for summary and discussion.

### Activity 2 Exploring the impact of separation and loss and our experiences of coping

Suggested time: 25 minutes

Explain that the aim of this activity is to explore the possible impacts of separation and loss and to look at experiences of coping.

1. Ask participants to work in pairs. Tell them they will have 10 minutes to share with each other an experience of separation or loss. Emphasise that they do not have to talk about a death. Say that if they choose to talk about a death, **they should not discuss the death of someone important to them.** Suggest some ideas to get people started, for example:

- first day at school
- leaving school
- moving home
- getting married
- leaving a job.

As trainer, think of your group and try to add ideas that might be particularly relevant to them and their local context.

2. Next ask the group to stay in pairs to discuss:

- what was difficult about the loss they have chosen to talk about
- any positive outcomes of the experience in the longer term
- what helped them cope.

Give them 10 minutes to do this.

3. Bring everyone together in the whole group and ask for volunteers to feed back the main points of their discussion. Bring out the following points:

- What feelings did people experience?
- Was any loss or separation *completely* negative or were there positive aspects?
- What has helped people cope? Make sure the discussion includes having someone to share your feelings and thoughts with, and note how time can often heal.
- What was positive about it in the longer term?

Allow five minutes for this.

4. Ask participants to reflect individually on the discussion and remember what helped people cope.

## Exploring death and dying

Be sensitive to how participants feel: some may want to listen rather than join in.

### Activity 3 How do we feel about death?

**Suggested time: 40 minutes**

Explain the aim of this activity is to explore feelings about death.

1. Ask participants to sit alone for a few moments and think of a death that was significant to them when they were younger.

#### Overhead/flipchart 2: Exploring the death of someone important to you

- What did you feel like at the time of the death?
- What were the attitudes of the people around you?
- How did you cope and who did you get support from, if anyone?
- How did you find out about the death?
- Is there anything you would have liked to be different about the way you found out about the death?
- What would have made it less painful or shocking?

Ask participants to consider the points individually for five minutes.

2. Ask participants to work in small groups and discuss these questions for 10 minutes. Ask each group to choose one person to feed back the main points to the whole group.
3. Next bring everyone back together. Ask the representative for each group to feed back, taking two minutes each. Record their answers on the flipchart.
4. Take 10 minutes to summarise the main points. Ask participants how the exercise could guide us to plan for the future.
5. Bring the activity to a close by emphasising the importance of planning for the future as a key part of memory work. Remind participants that the course will help parents living with HIV to plan memory books, the subject of Module 10. These memory books will keep alive in their children's minds the memory of them and the important things that the children will need to remember about their background. Explain to participants who are future guardians and carers that this activity helps them to be sensitive to the child's need to remember and talk about loved ones they have lost and where they come from, as well following through parents' plans for the child's future.

## Looking at children's fears of death and ways of preparing them to cope with separation and loss

Please note this topic is likely to make participants feel sad and possibly angry. Do not force individuals to participate in discussion. They may want to be passive and just listen. But be ready to answer any questions that the activity raises.

### Activity 4 Looking at the emotional impact of loss and separation caused by HIV and AIDS on children, and ways to meet their needs

**Suggested time: up to 2 hours if you are watching the video; 45 minutes if you make the presentation instead**

If possible, show the video as it gives more impact and support than the presentation.

#### **Option 1. The video *Everyone's Child***

1. Decide before the session whether you are going to show all of the video (85 minutes) or select parts. Explain to the group that the video covers the emotional and practical impacts of HIV and AIDS on children's lives. It also shows the supporting roles that community members can play.
2. Ask the group to watch the video and think about issues to discuss or questions to ask after it has finished.
3. When it has finished, gently start a discussion about it. Ask if it has given the group any ideas about preparing for the futures of their children. Be ready to answer any questions and allow 30 minutes for discussion. Give people time to reflect, compose themselves and think of questions.

#### **Option 2. Presentation**

Explain to the group that you are going to give a short presentation to help them understand the impact of separation and loss caused by HIV and AIDS on children, and to look at ways to meet children's needs. Ask the group to think about the points as they listen and decide which are most important. Ask them to be ready to discuss how these points might help parents prepare to meet the needs of their children in the future.

Take about 15 minutes to give the following presentation, having prepared well beforehand.

## Presentation

### 1. The impact of separation and loss

#### Separation

Separation makes children feel anxious. The younger the child and the less they understand the reason for the separation, the more anxious they might feel. This is known as separation anxiety, which has three main stages:

**protest** – an outward expression of what they are feeling, for example, in the form of anger, fear, or not understanding

**hopelessness** – the child becomes calmer, but seems sad and does not react much to comforting

**detachment** – if the separation continues for a long time, the child begins to respond to people again, but treats everyone the same. The child needs to re-learn how to relate to someone special.

However, remember each child is unique. Children may feel different levels of anxiety and they may not go through all three of these stages.

#### Loss

When children experience loss (in this context we are mainly talking about death), they may react with:

**shock** – for example, feeling numb

**confusion** – for example, not being able to do even simple things

**denial** – for example, searching for the person who has died, behaving as if they are still alive

**hurt** – this includes feeling sad and empty and longing for the person who has died

**loneliness**

**hopelessness** – for example, feeling helpless and unable to bring the dead person back; coming to realising they have gone forever

**guilt** – for example, thinking they did not do enough for the person when they were alive, or for having angry thoughts or feelings about them. Very young children who do not understand why a person has died sometimes feel they are to blame

**anxiety** – for example, worrying about the future and increased responsibilities

**anger and thoughts of “why me?”** – this can range from being irritable towards friends and family to angry outbursts to God or fate, nurses, doctors or even the person who has died.

It is best not to think of these reactions as stages. They can happen in a different order or come back again after being worked through once. With time, the child learns to **acknowledge** and then **accept** what has happened. The child can then start to reorganise his or her life, with others to help.

### 2. Meeting children’s needs

It is important to be clear about children’s emotional and physical needs. These all have to be planned for while the parent is still alive and while the child can be included in planning their futures.

**Emotional needs:** remind participants that earlier modules, particularly Module 2 on child growth and development, covered some of these needs at different ages. Remind the group of the following points:

- Children need to know in good time about their parent’s HIV status.
- It is important to strengthen the relationship between parent and child before the loss occurs to make them feel loved and trusted.

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- Allow the child to find out more about the parent's life and experiences. This encourages a sense of belonging and helps open the way for communication.
- It is important not to cling to the child, and to involve other family members or friends. This will encourage independence.
- If possible, parents should try to identify someone they can trust to provide consistent loving care for the future. When they have made an arrangement, the child should be involved in the planning. Children will recover better if they can stay with the same primary carer after losing a parent, until they become young adults. This avoids coping with more separations.
- Support can also come from many sources in the community if it is planned ahead. This might include other people who are familiar with the child, such as relatives, friends, teachers and local members of the church.
- Before and after loss, a child will need to be comforted and listened to. He or she should be encouraged to express his or her feelings. It is also important to validate what the child feels. Validation means acknowledging that the child is having the feelings he or she is describing. Try not to say that things will get better or that time will heal, as this approach does not meet the child's immediate needs. Validation is about acknowledging this is how the child feels right now.
- It is important to keep brothers and sisters together if possible. Research shows that they can provide emotional support to each other from early ages, as young as three or four.

### Physical needs

- The child will need to have somewhere to live and someone who will care for her or him physically, looking after her or his health and education.
- Again, the community can help support these children, and local church and AIDS support centres may be able to provide practical, and possibly financial, help.

After the presentation, gently start a discussion about what the group has learned and whether it has given them any ideas to prepare for the future of their children. Be ready to answer any questions. Allow 30 minutes for discussion. Give people time to reflect, compose themselves and think of questions.

## Reflection

You will need to be aware of participants' feelings in this last activity. Be ready to comfort anyone who is very upset.

Draw the session to a close. Acknowledge that the module has probably been emotionally tiring for everyone.

### Activity 5 Reflecting on the module

**Suggested time: 15 minutes**

Explain that the aim of this activity is for participants to reflect on what they have done in this module and to share key learning points with each other. Say that they can do this quietly with another person, but if anyone wants to speak to the whole group they are welcome to do so.

1. Ask participants to turn to the person sitting next to them and say how they would like to be remembered. Allow five minutes for this.
2. Ask each person to share with the same person how they are feeling and what they have learned from this session. Allow five minutes for this.
3. After five minutes, say that if anyone would like to share their thoughts with the rest of the group they are welcome to do so.
4. Close the module. Thank participants for their contributions and say you are looking forward to working with them on the next module. Remind participants that the next session builds on this one. It focuses on planning for more positive futures.

Make sure that everyone is feeling calm by the time they leave the session. An extra refreshment break to encourage people to talk among themselves might help participants to feel better before leaving.

# MODULE 6 – Trainer's notes

## Five stages of loss and bereavement

(Taken from *On Death and Dying* by Elizabeth Kubler-Ross, September 1992)

### 1. DENIAL AND ISOLATION

This is characterised by statements such as “No, not me, it cannot be true”. For example, on receiving an HIV-positive diagnosis, a person may say: “No, it cannot be true – the hospital must have got the results mixed up.” She or he may ask for further tests to be carried out in the hope that the initial diagnosis was wrong.

Denial is used by almost all people, not only during the first stages of illness, but also later on from time to time. Very often, people can consider the possibility of their own death for a while, but then have to put these thoughts away in order to continue with life. Denial functions as a buffer after unexpected shocking news. It allows the person to collect her or himself and mobilise other defences. Denial is usually a temporary defence and will soon be replaced by a partial acceptance. The need for denial exists in all people at the end of a person's life. The need comes and goes and the sensitive listener will acknowledge this and allow the person his or her defences without making him or her aware of the contradictions.

To summarise: the person's first reaction maybe a temporary state of shock from which she or he recuperates gradually. When the initial feeling of numbness begins to disappear, and the person can collect her or himself again, the usual response is “No, it cannot be me”. The person will gradually drop his/her denial and use less radical defence mechanisms.

### 2. ANGER

When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. It is characterised by questions such as “why me?” This stage can be very difficult to cope with for family and others surrounding the person. The anger can be displaced in all directions, projected on to the environment at different times. For example, if the reaction is “The doctors are no good, they are not experienced, they do not care,” the visiting family may be received in an unfriendly manner, making the meeting a painful event. They, in turn, may either respond with grief, guilt or shame, or even avoid future visits, which only increases the person's discomfort or anger.

A person who is given attention and time will soon reduce his or her angry demands. She or he will know that she or he is a valuable human being, and one that is cared for. Often, we do not think of the reasons why a person is angry and take it personally, when it has little to do with the person who has become the target of our anger. In this situation, it is important to understand and not to judge the person.

### 3. BARGAINING

Bargaining involves entering into some sort of an agreement which may postpone the inevitable happening. For example, “If God has decided to take me from this earth, and He's not responding to my angry pleas, then maybe He'll be more favourable if I ask Him nicely.” The patient feels that he or she may be rewarded for good behaviour. Bargaining includes an implicit promise that the patient will not ask for more if this one postponement is granted. Most bargains are made with God and are usually kept a secret or mentioned ‘between the lines’. Psychologically, promises may be associated with quiet guilt. It is therefore important to take such remarks seriously. It may be useful

to find out if the person really does feel guilty for not attending church more regularly or whatever it is, or if there are deeper unconscious hostile wishes which have led to such guilt. According to Kubler-Ross, none of her patients 'kept their promise'. In other words, they are like the children who say, "I will never fight my sister again if you let me go."

#### 4. DEPRESSION

When the terminally ill person can no longer deny his or her illness, and begins to get weaker, this numbness and anger will soon be replaced with a sense of great loss. Kubler-Ross suggests that we often tend to forget the preparatory grief that the terminally ill patient has to undergo in order to prepare him or herself for his or her final separation from this world. Kubler-Ross differentiates between two kinds of depression: reactive and preparatory.

**Reactive depression:** In this case the cause of the depression needs to be found, and some of the unrealistic guilt or shame that often accompanies the depression needs to be alleviated. This may involve dealing with practical matters and helping the reorganisation of the person's household, e.g. making fostering or adoption arrangements for children. Very often, the person's depression will be lifted quickly after these vital issues have been taken care of.

**Preparatory depression:** This type of depression is one that does not occur as a result of something that has happened in the past but is taking into account impending losses. At this stage the patient should not be encouraged to always look on the sunny side of things as this would mean that he or she would not be thinking about his or her impending death. In being allowed to express sorrow, he or she will find that final acceptance is much easier.

This second type of depression is usually a silent one, with little need for words. It is often approached better with a touch of the hand or a silent sitting together. There can also be a discrepancy between the patient's wish and readiness to die and the expectation of those in his or her environment to fight to live. It is this that causes the greatest grief and turmoil for terminally ill people.

#### 5. ACCEPTANCE

If the person has had enough time or has been given some help in working through the previous stages, she or he will reach a stage of acceptance. She or he will be tired, and in most cases, quite weak. She or he will also have a need to doze off or to sleep often and at brief intervals. There is a gradually increasing need to extend the hours of sleep, very similarly to that of the new born child, but in reverse order. Acceptance is almost void of feelings. It is as if the pain has gone, the struggle is over and there comes a time for 'the final rest before a long journey', as one person put it. This is also the time when the family needs more help, understanding and support than the dying person him or herself.

Communication then become more non-verbal than verbal. Moments of silence may be the most meaningful kind of communication at this time. We may just let him or her know that it is all right to say nothing when the important things are taken care of and it is only a question of time until she or he can close her or his eyes forever. The dying person, while accepting his or her impending death, still maintains hope.

## The phases of loss

### 1. Shock

This presents itself in a variety of ways, such as sleeplessness, yawning and tiredness, loss of appetite, 'dreamlike' behaviour, and an inability to concentrate, make decisions or absorb information.

**You can HELP by:** comforting and, above all, listening. Do practical tasks. Be available

and supportive, but not intrusive. Do not chatter: this can be very annoying as some people have a low tolerance to noise at this time. Provide drinks and light food but do not force the person to eat. Gently encourage her or him to undertake tasks such as funeral arrangements, telling others and so on. This will help the person to come to terms with the loss.

## 2. Denial

This often presents itself as an inability to talk about the situation and indeed some people continue to plan and live as if the dead person were still alive. Enquirers are often told "I'm fine", are dismissed or are forced to change the subject. It is not unusual for people in this phase to adopt phrases or even characteristics of the dead person. There will be an inability to cry, as this acknowledges the loss. During this phase, hyperactivity and anxiety are common.

**You can HELP by:** being there or not being there – depending on the person's wishes; actively listening. Although it takes courage, do not be afraid to talk about the dead person.

## 3. Yearning/pining

There will be feelings of being alone. There may be frequent bouts of crying at thoughts or objects that give reminders of the dead person. This process should not be interfered with, as it is a good sign that the loss is no longer being denied. The loss will feel increasingly real and with it will be a wish for the dead person to return and fill the void. Some people imagine they have heard the dead person. During this phase, which can last for months, people change their minds frequently – wanting to be alone, not wanting to be alone, wanting to be alone, and so on.

**You can HELP by:** being there or not being there, as the person wishes. Go through photos and openly talk of the dead person. Avoid platitudes such as "He's at peace now", "She had a good life", and so on.

Unless you have had a similar experience avoid phrases such as "I know how you feel". Be tolerant. Do not hurry to sort out clothes and belongings, but should someone want to do this do not stop them either. Some people feel they have to do it straight away. Allow them to weep, although you may find this uncomfortable.

## 4. Anger, guilt, apathy and bargaining

This is a strange mixture of emotions and people can become very frightened by them. They can feel nothing one minute and suddenly become angry either with the dead person for leaving them or those around for not helping properly. This can result in guilty feelings or regretful expressions such as "If only I had done this." There is often both anger and apathy towards making a new life, and even doing the basics like cleaning or preparing meals. Feelings of low self-esteem are often evident.

**You can HELP by:** being supportive. Accept the anger, although it can be profound and sometimes very damaging to a relationship. Be comforting and give hope. It is also useful to express positively what the person did for the dead person. Do not press him or her to eat but try to tempt him or her with small titbits.

## 5. Acceptance

This occurs for some people. It is a very gradual process and the length of time it takes can be governed by many things, such as how the person died, whether the relationship was good or bad, and previous bereavement experiences. As acceptance occurs, it often presents itself as a growing awareness of others, the ability to laugh again, appreciation of growing things and feelings of warmth for those who have been supportive. People often start to be more sociable. The 'bad' as well as the 'good' attributes of the dead person will be remembered and acknowledged. There will be increased feelings of self-confidence and self-esteem.

**You can HELP by:** encouraging and giving positive feedback. Be available, comforting and supportive when mistakes are made.