

HIV Counselling Series No. 7



Guidelines for Counselling Children who are Infected with HIV or Affected by HIV and AIDS



CANADIAN PUBLIC HEALTH ASSOCIATION
ASSOCIATION CANADIENNE DE SANTÉ PUBLIQUE



Canadian International
Development Agency

Agence canadienne
de développement international

Guidelines for Counselling Children who are Infected with HIV or Affected by HIV and AIDS

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First Edition January 2003

Produced by SAT (Southern African AIDS Training Programme)
with the financial support of the government of Canada provided
through the Canadian International Development Agency (CIDA)

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ISBN: 1-77928-0050-X

Foreword

This is the seventh publication in a series of guidelines for counselling people who are infected with HIV, who are concerned about being infected with HIV or who are living with or caring for people with AIDS. Each booklet offers practical guidance on specific counselling issues. The publications are designed for use by volunteer counsellors, non-professional counsellors and professional counsellors who do not have extensive experience in counselling in the context of HIV and AIDS.

The guidelines are the result of workshops organised under the SAT School Without Walls, bringing together professional counsellors, people living with HIV or AIDS, staff of AIDS Service Organisations and people working in the field addressed by the publication. A workshop on counselling children with HIV or children affected by HIV and AIDS was hosted by the Copperbelt HIV Education Programme (CHEP) in Zambia and facilitated by Jonathan Brakarsh and Clare Rudd of the Family Support Trust (FST) in Zimbabwe. These guidelines reflect the experiences of the counsellors and activists who participated in the workshop. Virginia Knight Tyson and Sarah Lee provided editorial assistance. Joel Chikwara drew the cartoons.

To date, SAT has published counselling guidelines in English and Portuguese on the following subjects:

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| 1: Disclosure of HIV Status | 4: Domestic Violence |
| 2: Child Sexual Abuse | 5: Survival Skills |
| 3: Palliative Care and Bereavement | 6: Basic Counselling Skills |

SAT is a project of the Canadian International Development Agency delivered by the Canadian Public Health Association. It has been at the forefront in supporting the community response to HIV and AIDS in Southern Africa since 1991. School Without Walls is an initiative to validate, promote and diffuse southern African experience and expertise in responding to HIV and AIDS. SAT is profoundly grateful to the volunteers and professionals who have made this and other publications possible.



Contents

Introduction	1
Re-cap on basic counselling good practice	2
Communicating with children	3
Gelly's story: The power of play	7
Issues for counsellors	8
A counsellor's testimony: Going that little bit further	10
The counselling process	11
HIV testing for children	15
Disclosure of HIV status	20
HIV and AIDS in the family	23
Farai's story: Learning the hard way	28
Talking to children about death	29
Contributing partners	33

Introduction

Throughout southern Africa, HIV and AIDS have **affected** millions of children. Many have already become orphans or are caring for sick parents, grandparents, siblings or other relatives. Many more have had their school and community life changed beyond recognition.

Meanwhile, other children are themselves **infected** with HIV, and often have to cope with ill health combined with social stigma. In some cases, such children experience the double trauma of coping with their own HIV status while also having lost their parents, brothers or sisters, for example.

Children are not just bystanders in the AIDS pandemic. Whether infected or affected, they have major psychosocial needs of their own. Frequently, however, these needs are neglected. This is often because adults fail to understand how children are emotionally affected and how they can be helped. Adults find it difficult to talk to children about such sensitive subjects as sex, illness and death. Their instinctive response is usually to protect children from painful topics. But this can create a conspiracy of silence and fear, or a situation where adults fail to acknowledge that children are already experiencing anxiety and pain and having to cope with these feelings on their own.

Trying to keep information about HIV and AIDS from children is difficult, if not impossible. It can also have negative consequences. We must be aware that children have different needs, perceptions, responses and reactions than adults. So, while being open and honest during counselling, the methods, language and information used should be specifically appropriate to the age and development level of the child in question.

This booklet provides guidance for counsellors working with children who are infected or affected by HIV and AIDS, including how to communicate with them about sensitive issues, how to identify their needs and provide appropriate support. It will be especially useful if used alongside SAT's Counselling Guidelines Number 6: Basic Counselling Skills – which provides an overall summary of 'good practice' in relation to AIDS counselling.

Re-cap on basic counselling good practice

Counselling children includes:

- Establishing helping relationships with children
- Helping children tell their story
- Listening attentively to children
- Giving children correct and appropriate information
- Helping children make informed decisions
- Helping children recognise and build on their strengths
- Helping children develop a positive attitude towards life.



Counselling children does not include:

- Making decisions on behalf of children
- Judging children
- Interrogating children
- Blaming children
- Preaching or lecturing to children
- Making promises you cannot keep
- Imposing your own beliefs on children
- Arguing with children.



Counselling is intended to:

- Help children cope with the emotions and challenges they experience when they discover they are infected with HIV
- Help children with HIV to make choices and decisions that will prolong their life and improve their quality of life
- Help children cope with the emotions and challenges they face when HIV and AIDS affects them, i.e. when a family member, friend or neighbour has HIV or AIDS.

Communicating with children

The basic 'good practice' outlined on the previous page is the same for AIDS counselling with people of any age, although some areas are different when counselling young clients. For example, children often find it particularly difficult to recognise what fears and emotions they are experiencing, let alone put them into words. Communication is the foundation of the relationship between counsellor and child. For this reason, practical ways must be found to communicate; ways that are effective not only for you, the counsellor, but, more importantly, for the child.

Communicating about sensitive issues

During counselling, children who are HIV+ or affected by HIV and AIDS should never be forced to tell their 'story'. If children cannot communicate about something, there will be good reasons why that is the case. The reasons might include:

- Traditions and customs pose barriers to their communication. For example, some cultures forbid children to disagree with adults.
- Children may feel embarrassed or ashamed to discuss HIV and AIDS with adults because it relates to taboo subjects, such as sex.
- Children may be too young to put their feelings or experiences into words. In practice, the counsellor must always consider the age of the children, how much they know, and their ability to express their knowledge or emotions.
- Children often fear hurting those they love. For example, they might hide their feelings in order to protect their parents, particularly if their parents are sick or unhappy.

Using the right tools

It is the counsellor's job to help the child overcome these barriers and to communicate freely. As a starting point, you need to meet children on their level. This involves using creative and non-threatening

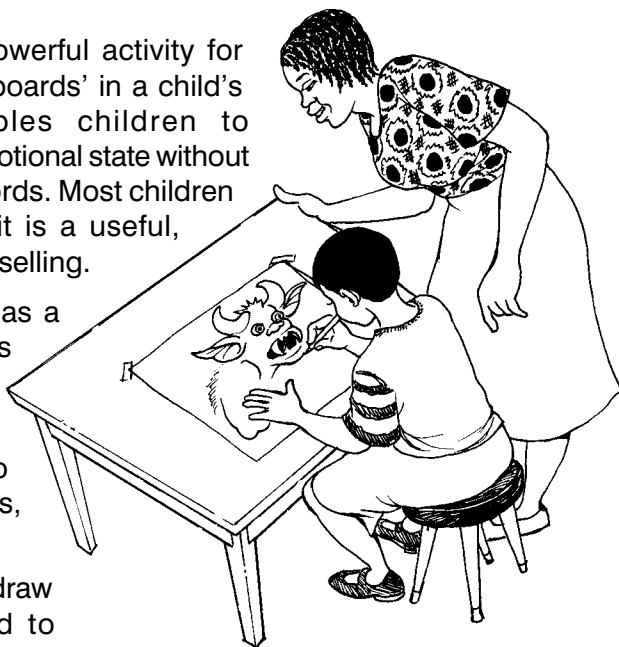
methods to explore sensitive issues and helping children to express their feelings. Following are some examples of appropriate tools. They can be used by counsellor and also by parents to continue discussions at home.

Drawing

Drawing can be a powerful activity for opening 'hidden cupboards' in a child's life. Drawing enables children to communicate their emotional state without having to put it into words. Most children enjoy drawing, and it is a useful, practical tool for counselling.

When using drawing as a counselling tool, it is helpful to:

- Give the child different materials to use, such as pencils, pens, paints.
- Ask the children to draw something related to what you would like them to explore. For example, ask them to 'Draw a picture of your family having fun' or 'Draw a picture of something that makes you angry'.
- Gently follow up by asking the children to describe what is happening in their drawing.
- Use 'open' questions to encourage them to talk more about what they have drawn and why. For example, 'How do the people in the drawing feel about what is happening?'



Storytelling

Children tend not to like lots of direct questions or long lectures. When they are finding it difficult to talk about painful issues, listening to a story about someone in a similar position can be very comforting. It can give children the sense of being understood, and it can help them to recognise that they are not alone. A story can also serve as a useful tool for problem solving around their own situation.

When using storytelling as a counselling tool, it is helpful to:

- Use a familiar story, fable or folktale to convey a message to the child, perhaps using animals to represent humans.
- Avoid using real names or events.
- At the end of the story, encourage the child to talk about what happened. For example, ask about the message of the story to confirm that the child has understood its relevance.
- If helpful, ask the children to make up their own story, based on a topic that you give them. For example, 'Tell me a story about a little girl who was very sad'.

Drama

Drama or role-play is an excellent way for children – and friends, siblings and other family members – to raise issues they want to communicate with others, but find difficult to discuss directly.

When using drama as a counselling tool, it is helpful to:

- Give the children a topic to perform – such as 'A day in my life' – that is related to issues you want to explore with them.
- After the performance, encourage the child to discuss what happened in the drama and what issues came up.
- Ask questions to explore specific areas, such as 'What was the happiest / saddest part of the day?'



Play

Adults often think play serves no serious purpose. Nevertheless, play is an important way that children explore their feelings about events and make sense of their world. When children play, much of their activity involves imitation or acting out – which helps us to begin to understand what type of emotions they are experiencing.

When using play as a counselling tool, it is helpful to:

- Give the child a variety of play materials, including simple everyday objects (such as boxes, string and sticks) and toys (such as human and animal figures, cars and doll houses).
- Ask the children to show you parts of their life using the play materials. For example: 'Show me what you like to do with your family'. While the child is using the objects to *show* you, you can ask him or her also to *tell* you what is happening.
- Follow and observe what the child is doing and do not take over the play. If you want to check that you have understood what the child is communicating, make comments – such as 'I see the mummy doll is so sick that she cannot get out of bed' – and see if the child agrees.
- If the child gets stuck and cannot proceed further, ask him or her questions such as 'What is going to happen next?' or 'Tell me about this person' (while pointing to the character that you are interested in). Such questions can help them to continue.

Gelly's story: The power of play

At the age of six, Gelly lost both her parents and a sibling to AIDS. After their deaths, she lived briefly with her grandmother until she too died. At seven, she was taken to a mission orphanage.

Here she kept to herself and seldom spoke to or interacted with others. Day after day, she sat by herself drawing in the sand.

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One day, one of the nuns asked Gelly if she could play with her. The nun observed that Gelly wasn't drawing in the sand, but was playing a game that she called 'graves'. Over and over again, Gelly would play this game in which all the people would die and be buried in the sand. By observing her play, the nun was able to explore and understand Gelly's feelings about the deaths of her family. Things that Gelly had difficulty expressing verbally were shown in her 'game', such as her fears about her own death and of getting close to anyone else in case they also died. In time, the nun used the game to gain Gelly's trust, to begin talking to her about her concerns and to care for her.



Issues for counsellors

Working with children who are HIV+ or who are affected by HIV and AIDS can be challenging and highly emotional, even for an experienced counsellor. It presents personal and professional issues that you should consider. These include:

Personal issues

- It is vital to be honest about your own feelings. These might include doubts about your own HIV status, fears about the status of your children and concerns about working with children facing death or bereavement.
- You must consider how such feelings might influence your behaviour and counselling skills when working with children.
- You need to separate emotional involvement with the families you are working with from emotional issues in your own life. To do this, you need to have your own support system in place, such as individual counselling or supervision by a professional colleague.

Cultural, traditional, religious and gender issues

- You need to be aware of your own opinions about and reactions to the cultural, traditional, religious and gender norms that influence children with HIV or children affected by HIV and AIDS.
- You need to consider which norms it would or would not be appropriate to raise and/or challenge during counselling.
- When dealing with death and dying, you might be tempted to impose your own religious beliefs on the children you are working with. You need to be very cautious about this, as your beliefs may not be the same as the children's and it may make them feel confused and pressured.

Confidentiality issues

Confidentiality is about respecting and withholding private information. It can pose challenges in relation to counselling children who are infected or affected by HIV and AIDS. For example, you might feel that releasing information about a child's situation would be in his or her best interests, but this might go against the family's wishes. It can also be a burden for children to keep their own information confidential – as they tend to be naturally spontaneous and struggle to keep secrets.

As a counsellor, you need to:

- Reassure the children and their family that things discussed during counselling sessions will remain confidential.
- Explain when confidentiality might be broken, such as life-threatening situations affecting the child's physical welfare.
- Explore the children's underlying fears about disclosing information and empower them to talk freely about the difficulties involved in keeping information confidential.
- Encourage the children and their family to reach consensus about confidentiality. If this is impossible, get permission from them as individuals to share the relevant information with the others involved. If all measures fail, consult another counsellor or refer to another institution, such as a church or support group.

Advocacy issues

Advocacy involves standing up for the rights of your clients and helping them overcome obstacles by taking action with the community and authorities. Advocacy is particularly important when working with children because their opinions are often ignored. Where possible, they should be supported to speak for themselves. Where not possible, you must ensure that you accurately represent their true feelings. When advocating for children with HIV or children affected by HIV and AIDS it is vital to:

- Have all of the necessary information available to you. Otherwise, it might be difficult to get others to back you up or to convince the authorities to take action.
- Agree on issues of confidentiality with the children, such as whether they are happy for the authorities to know their names.

A counsellor's testimony: Going that little bit further

‘Having worked as an AIDS counsellor with families for six years, I have learned that doing my job effectively often involves much more than counselling the children and families that are affected. Due to the huge stigma associated with being infected, we often need to become advocates and to directly challenge the people or institutions that reinforce the stigma of HIV and AIDS, beginning with our own families, schools and communities. We often need to stand up for the rights of our child clients who are HIV positive.

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‘Recently, students at school were teasing a young boy who I was counselling. He believed that the harassment was due to his disclosure of being HIV positive. When I learned about this, I used the opportunity to arrange an outreach talk about HIV and AIDS to students and teachers at the school. By directly addressing the myths and misconceptions that people had about HIV and AIDS (and there were lots!) and challenging their reactions to HIV-positive people, we were able to show that this type of behaviour was unnecessary and unacceptable.’

The counselling process

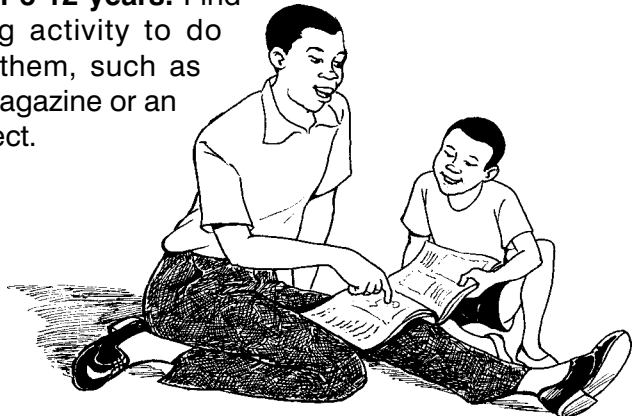
'Joining' with children

To counsel children, you must form a good relationship with them from the very beginning. This is often called 'joining'. It includes greeting the children and talking about something that is easy for them to discuss with you. As you talk together, they can get to know you and decide whether they are comfortable with you. Some examples of how to join with children of different ages include:

- **For children under 5 years:** Get down on the floor with them and find a game they like to play.

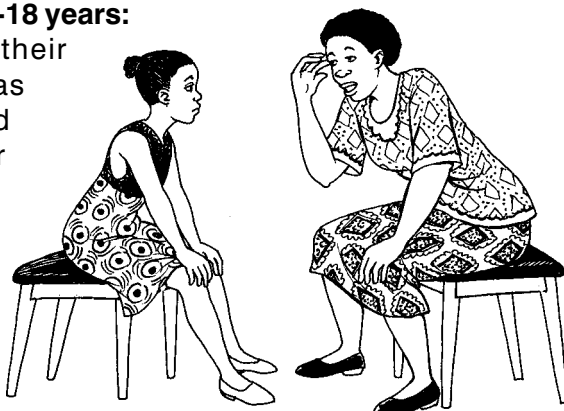


- **For children of 6-12 years:** Find a fun, relaxing activity to do together with them, such as discussing a magazine or an interesting object.



- **For teenagers of 13-18 years:**

Find out about their interests, such as sports or music, and ask them about their likes and dislikes.



Strategies for working one-to-one with a child

As a counsellor working in this area, you may be involved in one-to-one sessions with children living with HIV, or children affected by the impact of HIV and AIDS on their family. In this context, you need to:

- Follow the usual 'good practice' for counselling work, such as preparing yourself for the session, creating a welcoming environment and keeping a record of important developments. (See SAT's Counselling Guidelines Number 6: Basic Counselling Skills for further information.)
- Recognise that whatever your training and school of thought about counselling, your work needs to be child-centred. This means seeing counselling as a two-way process, with the child at the heart of it as an active participant rather than just a recipient.
- Establish boundaries of confidentiality with the children. For example, ask them if there are any issues they do not wish to discuss in family sessions involving their parents.
- Continually acknowledge and validate what the children feel and say about their situation, rather than making presumptions or waiting to hear what adults have to say.
- Observe what the children *do* as well as say. For example, what is their body language and eye contact telling you?

- Encourage children – whether they are infected or affected by HIV and AIDS – to access support *in addition to* the counselling sessions, for example from a self-help group of their peers. This will help to ensure that they do not become over-dependent on you or your sessions and that they have ongoing sources of support.

Strategies for working with a family

Family counselling can include having different sessions with various family members. This might mean working with one or both parents, one parent and a child, or children on their own. In this context, you need to:

- Follow the usual ‘good practice’ for counselling work (see above).
- Discuss the advantages and disadvantages of each type of approach and agree with the child and the family who should and should not be present in each session.
- Recognise that you often need to work in different ways with different family members – to help them deal with their individual issues. This might involve using different methods – for example, a child might like to use drawing, but a teenager might prefer to use drama.
- Acknowledge that in practice the family is often the entry point for a counsellor to work with children. So, before you start work, it is important to establish a good relationship with the child and also with other family members, especially the parents.
- Agree and maintain confidentiality about the issues raised by all those involved, including the children and parents.
- Work with the children and their families to agree on creative and supportive ways to explore family relationship problems.
- Explore with parents how and why traditions can make it hard for children to talk openly. If necessary, involve someone else – such as a youth worker – to facilitate child / parent communication.
- Build a sense of team spirit. For example, ensure that the sessions do not focus solely on the child or family member who is HIV+, but that they also involve discussions about how everybody feels about family life and HIV and AIDS.

- Encourage parents to continue discussions with the child and other family members at home.
- Encourage children and family members to access other support in addition to the counselling sessions as, for example, from a self-help group. This will help to ensure that they do not become over-dependent on you and that they have ongoing sources of support.

Traditional approaches to counselling

When families expect you to provide counselling in a more traditional manner, you need to:

- Act as an intermediary to facilitate dialogue between the child and the family – to ensure that both sets of wishes are considered.
- Explore with the child and the family the type of outcomes – both positive and negative – that can result from traditions and customs.
- Include significant and relevant people in the counselling process, such as grandparents, community leaders and traditional healers.
- Help families get community support so they can perform any cultural rituals that are necessary.

HIV testing for children

HIV testing brings up many complex issues. Counsellors need to be aware of these issues and discuss them with children and their families. It is important to consider both the advantages and disadvantages involved.

Advantages of testing

If children know they are HIV+, they can:

- Access information and services to prolong their life, for example by improving their diet and taking exercise.
- Gain the support of others in a similar situation, for example by joining a support group of peers.
- Be helped to understand how to avoid infecting others.
- Become a role model by showing that you can live well with HIV.
- Experience the relief of knowing the truth rather than being worried and stressed about the unknown.

Disadvantages of testing

If children know they are HIV+, they might:

- Not fully understand the situation. They may only understand the negative implications and not be aware that they can live positively.
- Disclose their status without being aware of the possible consequences.
- Feel angry and resentful, or feel depressed and lose hope.

When to test

Ideally the child decides this, with guidance from the family (where appropriate). In practice, parents might consider testing their child if:

- They themselves are HIV+ and their child is very young.

- The child is sexually active, or there is strong evidence of sexual abuse.
- The child has been at risk due to unsafe blood or un-sterilised needles.
- A confirmed HIV diagnosis would have important implications for medical treatment for the child.

Should a child be informed about being tested?

Children have the right to voice their opinions about issues that affect their lives. Even if they are young, they have the right to be given information and support to help them understand their situation and be involved in making decisions about what is best for them.

In practice, exactly what a child should be told depends on his or her individual level of development and emotional maturity. Counsellors face the challenge of finding a balance between listening to the child's concerns, respecting the parents' wishes and ensuring the child's overall welfare.

To achieve this balance, you need to:

- Make sure that you are well informed about the laws regarding the age of consent for HIV testing in your country.



- Discuss with the parents what information they have given to the child beforehand – so that you can reinforce what has already been said, correct any misconceptions and introduce additional details.
- Enable the child to feel in control and listened to. Give the child information appropriate to his or her level of development and – using tools such as drawing and play – explain what an HIV test involves.
- Recognise that an HIV test may raise different issues for children of different ages. For example, young children might be most scared of the physical pain involved in having their blood taken.
- Give honest answers to the children and do not hide information, even if it might be difficult for you to say and for them to hear.

Pre-test counselling for children

Children should never be rushed into making decisions, especially something as personal and important as testing for HIV. In a pre-test session, a child might come alone or be accompanied by a support person, such as a parent or friend. As a counsellor, you should:

- Remember that if the child has come alone, family consent may be needed before proceeding with an HIV test.
- Create a friendly and private environment. If adults are present and the child is comfortable with that, proceed. If the child is not comfortable, ask the adults to wait somewhere outside.
- Gain the child's confidence and trust so that the child can speak freely about him or herself, the family and HIV and AIDS.
- Explore the child's feelings about being in the session and address any fears the child might have.
- Assess the child's knowledge and understanding of HIV and AIDS and find out what else the child wants to know.
- Answer the child's questions accurately and honestly, but remember that the information you provide must be appropriate to the child's age and level of development.

- Explain the testing procedure accurately. Explore and try to address any worries, fears and anxieties that the children might have about the process. Do not lie to try to protect them (such as promising that the blood test will not hurt).
- Explain the possible results of the test – negative, positive and indeterminate – and what each might mean for the child.
- Discuss who will receive the results, how they will be given and who will provide support, especially if the result shows the child is HIV+.
- Stress the benefits and importance of coming back for test result.
- If the child does not seem ready for a test or asks for more time, offer the child a further pre-test session. Encourage the support person to come along too.

Post-test counselling for children

In a post-test session, a child should not be rushed into receiving the result, but should be gently supported to accept the truth. One or more sessions should be offered to a child to cope with the result, especially if it is positive. As a counsellor, you should:

- Remember that if the child has come alone, family consent may still be needed before proceeding.
- As with pre-test counselling, gain the child's confidence and trust so that the child can speak freely about him or herself, the family and HIV and AIDS. Also, try to create a friendly and private environment.
- Check if the person that was previously identified to provide support is present. If that person is not, ask the child if he or she would like to make another appointment or if someone else can provide support.
- Briefly re-assess how much of the information given in the pre-test session the child has retained.
- Assess if the children are ready for their result. Check any preconceptions the children have and explore any fears. If the children say they are not ready, ask when they think they will be ready and make a plan for that.

- If the child is ready, give the result. Follow the 'good practice' procedure for post-test counselling (see SAT's Counselling Guidelines Number 6: Basic Counselling Skills), but adapt your approach to the development level of the child.

Whether the result is positive or negative:

- Allow the child some time to react. Be supportive throughout the reaction period, allowing tears, silences, anger and despair.
- Answer the child's questions. If the child asks for further information, provide it yourself or refer the child to another person that can help them.
- Make sure that the children and, if present, their families understand and accept the result. For example, ask them to say the result out loud and to repeat the key points that you have made. Also, ask the children about their immediate plans – to explore how they will access support from others.
- Be aware of the children's level of energy and concentration. If they are ready to receive more information and support at this session, continue. If not, arrange another session soon.



Disclosure of HIV status

Issues around disclosure

Disclosure is the process of sharing information about a person's HIV status with others. Whether it is the child or a member of the family that is HIV positive, counsellors need to think very carefully about the disclosure of HIV+ status to a child. This is because it may have a number of implications depending upon:

- How much information is disclosed.
- To whom the status is disclosed (for example, the child, siblings, relatives, the school or the community).
- When the status is disclosed.
- How the status is disclosed.

Counsellors and parents often find it difficult to explain to children that they or someone they love is HIV+. This may be due to:

- Traditional and cultural taboos – such as about talking about sex, death and witchcraft – which prevent adults from talking openly and honestly with children.
- The presence of strong emotional reactions that may make talking about the child or relative's status difficult.
- Not knowing exactly what to say to the child and fearing being asked questions that are difficult or impossible to answer.
- The adult's desire to protect children from bad news.

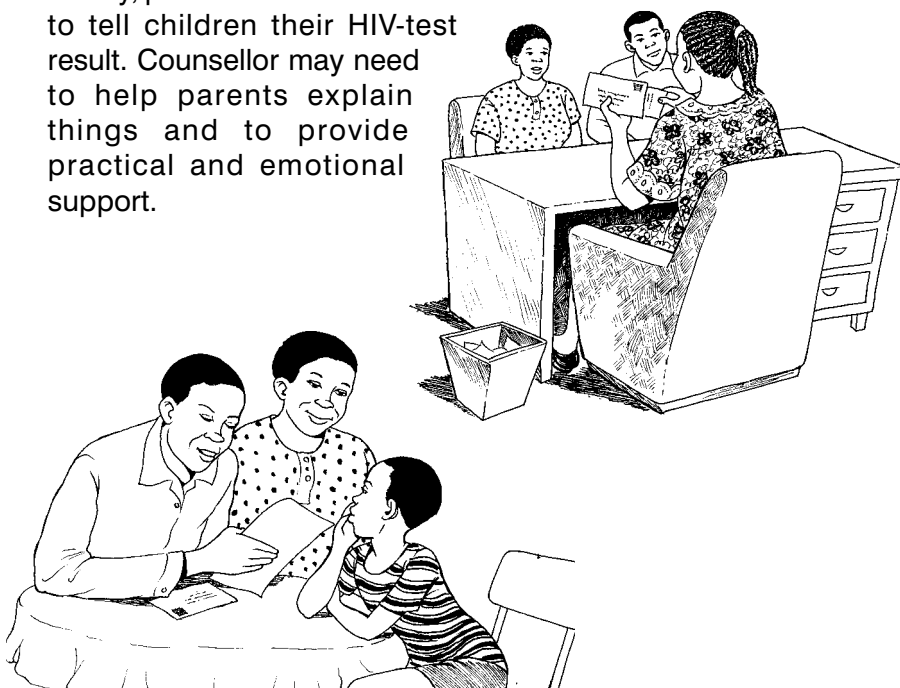
With support, children are usually able to deal with the realities of HIV and AIDS. Problems are more likely to arise when adults attempt to hide the truth and hide their emotions.

When children are forced or encouraged to hide their emotions, they may act them out in their behaviour – for example, wetting their bed, lying, having frequent headaches or stomach upsets.

By giving children simple, concrete and direct information (relevant to their age and maturity), their confusion, fantasies and nightmares can be avoided. It also means that children will not discover information through rumours or jokes in the wider community or at school.

When a child is HIV+

- As noted previously (see Post-test counselling), it is vital to provide a supportive environment for the disclosure of a child's HIV status, whether negative or positive. This includes ensuring that the child can express his or her emotions freely and openly.
- Ideally, parents should be the ones to tell children their HIV-test result. Counsellor may need to help parents explain things and to provide practical and emotional support.



- The time to disclose HIV+ status to a child should be determined by the child's level of development and emotional maturity, combined with the readiness and comfort of the parents to talk about such a sensitive topic. In practice, children as young as five or six years may be old enough to understand about living with HIV.

- Disclosure of HIV-test results to young children should be a process. Parents should start the process as soon as they know the child's HIV+ test result, but the speed and way in which they proceed will depend on the individual child and the circumstances.

When a parent or sibling is HIV+

Often parents or siblings who are HIV+ find it difficult to talk to children about their status. As a counsellor, you can facilitate the family to cope better. In practice, you need to:

- Encourage the children to discuss their anxieties. For example, help them to express fears for both the HIV+ person and for themselves (such as that they will be left alone).
- From the very beginning, help children establish systems of support – so that they are in place if the parent or sibling should become ill.
- Gently explore thoughts about death and life after death. Talk openly, but in a way that is appropriate to the children's age as well as their cultural and religious background.
- Ensure that the children know how to avoid HIV infection. For example, ensure that they can care for a sick family member safely, and that they understand safer sex practices if they are sexually active.
- Encourage children to join their HIV+ parent or sibling in positive living. This helps create a sense of joint action and helps children stay healthy and occupied.

Ongoing counselling and support

Whether it is a child or member of the child's family who is HIV+, remember that the role of a counsellor does not stop with the disclosure of HIV status. In fact, a counsellor's work may be even more vital over the following months and years. This extends to the stage when the family faces sickness and bereavement.

HIV and AIDS in the family

Emotional and psychological responses

Once children know that they or a member of their family is HIV+, they are emotionally affected. Counsellors often witness a range of strong emotional reactions, from grief to anger, denial to despair.

It is useful to understand the different ways children might react to the arrival – or return – of HIV and AIDS in their family and the ways in which counsellors might deal with these reactions and support the child and the family:

Denial

Denial is when someone chooses to ignore or disbelieve the facts. It is often a temporary coping mechanism in reaction to a HIV+ test result – the individual does not or cannot accept the reality of the situation. For example, if a parent has tested positive, a child might behave as if nothing has happened – because the child does not want to face the possibility that his or her parent might become sick or die. As a counsellor, you need to:

- Accept the child's denial and allow the child time to accept the HIV+ result.
- Explore any underlying fears that may be causing the child's denial.
- Acknowledge the child's fears and explain that these are normal.
- Reinforce the child's knowledge about HIV and AIDS by giving information in a simple manner, especially about how living positively can prolong life.
- Whoever is HIV+, motivate the whole family to live positively – by looking at their diet, exercise and stress management, as well as ensuring early treatment of opportunistic infections.
- When children are ready, refer them to peer support groups or other relevant resources in their local area.

Blame

People often look for others to blame about HIV and AIDS. They ask themselves 'Who is responsible?' or 'Whose fault is it?'. For example, children might blame their father for infecting their mother. Or children who are HIV+ might blame a family member who sexually abused them.

Although a natural response, blame can have negative effects, both within families and communities. As a counsellor, you need to:

- Explore the reasons why the child is blaming others.
- Give accurate and age-appropriate information about how HIV is and is not transmitted.
- Encourage the child to focus on the future instead of things that happened in the past and things that cannot be changed.
- Help the child and the family to communicate openly with each other, rather than keeping feelings of blame bottled up inside.
- Explore what other sources of support are available to the child, such as the extended family, school or community group.



Guilt

Sometimes, people feel guilty about HIV and AIDS. For example, young children might believe they have done something wrong to cause their parents to be HIV+. Or HIV+ children might feel guilty because it happened through sexual activity, behaviour of which their parents would not approve.

Guilt can lead children and adults to resist disclosure of HIV+ status and fail to begin living positively. This can make it more difficult for the family to talk openly and be supportive. As a counsellor, you need to:

- Allow the child to freely express any feelings of guilt, and explore the reasons behind those feelings.
- Give accurate and age-appropriate information about how HIV is and is not transmitted.
- Help children to share their problems with their family and to de-personalise the guilt, so that they do not feel isolated.
- Allow children to work through their feelings of guilt at their own pace, while feeling supported all the way.

Anger

Anger is a natural reaction when we are unhappy with a situation and want it to change. It can be expressed outwardly or inwardly. For example, children who are HIV+ might shout or show aggression if they blame someone else for their infection. Or, orphaned children might turn their anger in on themselves because they were unable to prevent their parents from dying. As a counsellor, you need to:

- Recognise that anger is a normal and understandable reaction.
- Allow children to express feelings of anger freely, and explore the thoughts and feelings behind their anger.
- Suggest practical ways for children and their families to express anger safely. These might include crying, hitting a pillow, doing a role-play or painting a picture.

Fear and shock

Fear is a survival instinct that we use to cope with a threatening situation. Children are often very scared by the sickness or death of a parent, and the uncertainty of their future.

Shock is another coping mechanism that we use to protect ourselves. It is often associated with feelings of numbness, confusion and weakness. For example, a child who has been told that he or she is HIV+ might initially behave as if nothing has happened.

As a counsellor, you need to:

- Encourage children to talk about their fears and reassure them that it is quite normal to feel frightened.
- Correct misconceptions that are fuelling the child's fears and give age-appropriate information, for example, about how people infected with HIV can live positively to prolong their lives.
- Help the child to come out of shock, for example, by discussing the facts about the situation and the possibilities of positive living.
- Explore the practical options available to the child, such as referring the child to a peer support group that provides more specialised help.
- Encourage family therapy, so that the child does not worry alone.

Social effects

The social effects experienced by children who are HIV+ or affected by HIV and AIDS are many and various. For example, a child whose parents or older siblings are HIV+ might face increased responsibility and experience a drop in the child's school performance. Or, a child who is HIV+ might act out rebellious behaviour (such as drinking alcohol or playing truant from school) or experience rejection by friends and neighbours. In particular, children often experience stigma.

Stigma is a negative moral judgement attached to a person's situation, behaviour or status. Stigma may arise from cultural, traditional or religious beliefs and can be perpetuated by social isolation. For example, a child diagnosed as HIV+ might be teased with AIDS jokes

in the playground and have no one to play with. Or, an orphaned child might be labelled an AIDS orphan, or become isolated from friends because the family can no longer afford to send him or her to school.



As a counsellor, you need to:

- Explore the social effects that the child is experiencing and discuss why other people might behave in a certain way.
- Provide the child with age-appropriate information, including straightforward facts about how HIV is and is not transmitted.
- Provide a safe environment for the child to express emotions. You can achieve this by collaborating with the people that matter most in the child's world and exploring who can provide practical and emotional support. This might include the child's family, school, support groups, government bodies, non-governmental organisations (NGOs), community-based organisations (CBOs) and churches.
- If possible and appropriate, encourage the child and the family to be positive role models – by showing their community that it is possible to live positively with HIV and AIDS.

Farai's story: Learning the hard way

Farai was the nine-year-old only child of a commercial sex worker who had AIDS. She knew about her mother's profession. At school she had been told about the people who get AIDS – truck drivers, soldiers and sex workers. Farai had worried about her mother for a long time, but never knew how to talk to her about her worries.

When Farai's mother was too sick to work, one of her sex worker friends took Farai to her mother's village in the rural areas. Farai's mother never talked to her about the move and Farai didn't realise it would mean changing schools, friends and her way of life. When she arrived at the village, nobody there spoke to Farai about her mother's condition. One day, Farai overheard her grandmother discussing her mother's illness with her uncles. Still nobody talked to Farai. She felt guilty and responsible for her mother's illness. She understood that her mother had contracted AIDS whilst earning money to support her and, therefore, felt it was her fault. Farai had no one to talk to about this.

Farai had worried about her mother for a long time, but never knew how to talk to her about her worries.

When her mother died, Farai felt that it was all her fault and ran away from the village. Luckily, she was 'rescued' by a home-based care nurse working in a nearby village. Having taken the time to hear Farai's story, the nurse began to help the girl rebuild her life.

Talking to children about death

Depending on their age, children go through a variety of stages in their understanding of death. It is useful for counsellors to be aware of this:

Below 5 years

Children of this age tend to see death as reversible and temporary. They do not see it as final. Small children are able to use the word death without understanding its full meaning. They do not see that death may happen to them and they may believe it is something they can avoid. They may also have misconceptions about what causes death. Explanations about death to children of this age should be brief, simple and concrete, such as: 'When people die they do not breathe anymore' or 'When dogs die they do not bark anymore'.

From 5-10 years

At this age, children gradually develop an understanding of death as irreversible. They come to understand that all living things die and that they too will die some day. At around the age of seven, children grasp that death is unavoidable and universal, even though they often resist the idea of death as a possibility for themselves. Like younger children, they need concrete explanations, although they sometimes exhibit 'magical thinking', such as thinking that the dead can see or hear the living.

From 10 years through adolescence

After the age of ten, children come to understand the true long-term consequences of death. They begin to reflect on fairness and unfairness, and fate. During adolescence, children are able to pick up inconsistencies in the information they receive. Teenagers may also become interested in looking for the meaning of life. If children in this stage experience death within the family, they tend to be able to understand explanations about the facts surrounding the death.

Preparing children for their own or a loved one's death

Whether a child or a child's family member is HIV+, you can help the child to prepare for death by:

- Remembering that children from 18 months to about five years have 'magical thinking'. They may fear their own powers or believe they have caused themselves or others to be HIV+, for example, by not doing well in school or not following a traditional custom.
- Communicating openly, honestly and factually. This involves giving information that is adjusted to the child's age. Avoid using abstract explanations, such as 'You will go on a long journey' or 'Your mother has gone to sleep'.
- Allowing the child to express anger or fear and helping the child to do so without harming himself or herself or anyone else.
- Acknowledging that a child's most natural reaction to death might be denial. Help the child work through this by gently, but continually, discussing the facts about HIV and AIDS and enabling the child to express fears and to ask questions.
- Ensuring that the child is not alone with worries and fears. For example, encourage family members to discuss issues around death and bereavement at their home, not just at the counselling sessions. Also, where appropriate, consider involving others – such as a church leader – in counselling the child about what death and dying mean within their culture and religion.
- Allowing children to discuss how they would like themselves or their family member to be remembered. For example, they might like to prepare a 'memory book' of drawings and poems.



Supporting children after the death of a loved one

If a child's parent or sibling has died of AIDS, you can help to support the child within counselling sessions by:

- Giving children time to think about the death. Allow them to ask questions, but also accept their silences. It may also be useful to look at photos, discuss memories and visit the grave.
- Accept that the child may engage in searching behaviour, such as physically looking for the deceased. Use this as an opportunity to accompany the child and to gently confirm the reality of death.
- Allow the children to express anger or fears and enable the child to do so without harming himself or herself or anyone else.
- Without rejecting the child's feelings, provide simple and honest repetitions of the facts about what has happened. For example, say 'I know it's hard to believe that your mother has died, but her body was weak and tired and couldn't carry on'.
- Be prepared to discuss questions relating to the child's religious or cultural beliefs. For example, the child might ask things such as 'Why has God taken my brother away?' Never imply that AIDS or death is a form of punishment from God, 'the spirits' or a person.
- Help to make the loss real for the child. For example, allow the child to participate in rituals, such as wakes and funerals, and to keep reminders of the dead family member around.
- Never impose expectations on the child such as saying 'You will definitely feel much better in three months time' or 'It's time you got on with your life'.
- Encourage emotional coping within the whole family and local community. For example, try to ensure continuity in other areas of the child's life at home and school. Also, avoid the child being unnecessarily separated from other loved ones, such as siblings, and address any fears that the child might have about the future of the family.

Contributing partners

The following organisations contributed their time, experience and expertise to the production of this publication:

- Associacio Reconstruindo a Esperanca, Mozambique
- Copperbelt Health Education Project (CHEP), Zambia
- Cotlands, South Africa
- Family AIDS Caring Trust (FACT), Zimbabwe
- Family Health Trust (FHT), Zambia
- Family Support Trust (FST), Zimbabwe
- Faraja Trust Fund (FTF), Tanzania
- Intervention Counselling and Care Project (ICOCA), Malawi
- Island Hospice Service, Zimbabwe
- Kara Counselling, Zambia
- Kimara Peer Educators, Tanzania
- Positive Women: Voices and Choices, Zimbabwe
- St. Francis Hospital (AIDS Care and Prevention Project), Zambia
- The Centre, Zimbabwe
- The Zimbabwe Institute of Systemic Therapy – CONNECT, Zimbabwe
- Youth Net and Counselling Organisation (YONECO), Malawi
- YWCA Child Crisis Centre, Zambia

