

Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment

for Health Care Workers working with Children and Families Affected by HIV and AIDS



Psychosocial Wellbeing For All Children

REPSSI is a regional non-governmental organisation working with partners to promote psychosocial care and support (PSS) for children affected by HIV and AIDS, poverty and conflict in East and Southern Africa.



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Foreword

The psychosocial aspects of paediatric HIV treatment are very closely linked to the biomedical ones. Adherence, treatment literacy, disclosure and stigma are all irrevocably linked to treatment outcomes. In the old days, when choosing the right doctor, people used to refer to “bedside manner.” With regard to paediatric HIV treatment nothing could be more important than an integration of psychosocial and biomedical issues and approaches. However with the advent of ART, the emphasis is now on keeping children out of bed, healthy, active, happy and normal. This comprehensive package is designed for health care workers to mainstream psychosocial support into Paediatric HIV treatment focusing on the wellbeing of the whole child.

A handwritten signature in black ink, appearing to read 'Nuni' with a stylized, overlapping 'H'.

Noreen Huni
Executive Director,
REPSSI, May, 2008

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Chapter One: Introduction

Introduction: Background and rationale

What do we mean by mainstreaming psychosocial support (PSS) into paediatric HIV treatment?

Throughout its work with governments, civil society organisations, communities, families and children, REPSSI has learnt a number of lessons. One of the lessons learnt is that stakeholders working with children often treat psychosocial support as an independent aspect of childcare that should have its own vertical programming. This approach has not maximised the psychosocial support benefits that children receive. REPSSI has adopted the mainstreaming approach in order to maximise the reach of children with psychosocial services, as well as to ensure that approaches to vulnerable children's programming become more holistic, sustainable and adequately embrace the voices and concerns of the target population.

By mainstreaming psychosocial support, we try to make sure that the child feels socially and emotionally supported in every part of life – at home, in the classroom, on the playground, in the street, on the way to school, at the clinic, at the soup



kitchen, at the kids club etc. Mainstreaming psychosocial support means making sure that this “stream or river” of wellbeing flows widely, strongly and continuously in and around the child.

In this instance, the focus of attention for mainstreaming is the clinic, and the programmatic area into which PSS is being mainstreamed, is paediatric HIV treatment.

In terms of the pyramid on the following page, by mainstreaming PSS into clinics at this level, it is possible to offer PSS to all children who are accessing treatment for HIV through local clinics and hospitals, and in this way it becomes possible to reach greater numbers of children.

About this package

HIV and AIDS invariably cause psychological and social suffering for children, families and communities. Whilst addressing the effects of the pandemic, attention needs to be paid to both its psychosocial and biomedical aspects. REPSSI and its partners decided that there was a need for more information about PSS in paediatric HIV and AIDS treatment and initiated a collaboration with partners in the REPSSI countries of operation in order to begin the process of providing it. A literature review was commissioned and several meetings were held with stakeholders in the field. This resulted in a decision to produce a package that would assist health care workers to look at paediatric HIV and AIDS

treatment through a Psychosocial Care and Support (PSS) tinted lens. The package would include practical ideas and user-friendly guidelines about how to offer PSS to children and their caregivers.

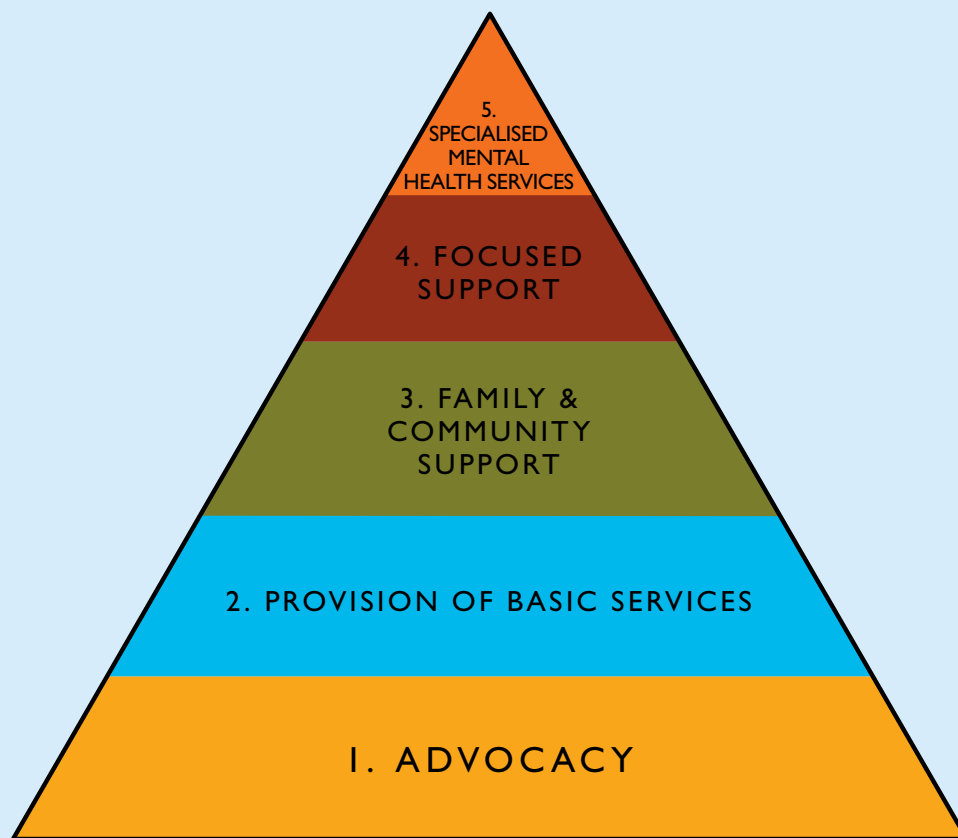
The literature reviewed stated unequivocally that all children need love, support, reassurance and acceptance, as well as a sense of belonging in order to thrive and cope with life's difficulties. Children affected by HIV and AIDS often suffer severe emotional setbacks which create a special vulnerability to emotional distress. The source of this distress is multiple: the illness itself; the loss of loved ones; isolation and abandonment due to rejection and stigma; low self esteem; grief; feelings of guilt, despair and suicidal thoughts. These emotional factors are exacerbated by material pressures such as poverty and unemployment. Children and families attending a local clinic or hospital provide a vital point of contact for mainstreaming PSS in paediatric HIV treatment. REPSSI aims to maximise this opportunity by helping to supply health care workers with practical skills in PSS. Our ultimate aim is to offer the kind of support to families that will assist them in facing the challenges of paediatric HIV and AIDS with confidence, strength and hope.

This publication aims to be thorough and detailed. It also includes, though, a set of easily accessible theory and practice cards that summarise and simplify the material, and offer action guidelines for easy use at community level. The main

body of the publication, the Theory to Practice sections, the check-lists and certain supplementary resources that have also been included, will be referred to as “the package”.

Key messages of this package

- Children living with HIV and AIDS are not merely the objects of the HIV and AIDS epidemic. They need to be consulted and involved as primary partners during all the interventions that are designed to improve their wellbeing. The exact nature of this partnership will be determined by their age.
- All children are unique. It is important that their individual psychosocial needs are identified and catered for. Prescribed blanket responses do not take individual difference into account, especially when these responses are based on stereotyping and categorisation.
- The most important sustainable resource for children is the everyday care and support provided by families, friends, teachers, religious groups and communities. It is this resource that health care workers need to strengthen, expand and support.
- It is important to involve the caregiver and family members who are immediately involved with the child as much as possible.
- A caregiver can only give support to children if her or his own needs are recognised and addressed.
- Health care workers have a vital role to play in supporting children and caregivers and ensuring that HIV and AIDS



Multi-layered, integrated psychosocial support

There are many different forms of psychosocial support. These may be offered at different levels to support children, families and communities. The following model may be used to consider the various levels at which PSS may be structured.

Levels of Psychosocial Support (PSS)

5. Specialised Mental Health Services:

Psychiatric, clinical psychological, specialised traditional healer services for the few children with more severe responses

4. Focused Support:

Additional non-specialised support for children who are not coping and who are showing signs of distress

3. Family and Community Support:

Everyday care and support provided by caregivers, friends and community members

2. Provision of Basic Services:

Shelter, food, health and education, into which PSS needs to be mainstreamed, to reach many children and support ways of coping.

1. Advocacy:

Influencing policy and changes to the social conditions that affect the wellbeing of millions of children

The more one focuses on the lower levels of this pyramid, the more impact one has on more children.



treatment has a positive outcome.

- Health care workers themselves need to receive psychosocial support and training in order to cope with the emotional demands of their work

Who is this package for?

- Health care workers at their places of work, in clinics and in the broader community – it is designed to assist them in their work with the community in general and with caregivers of children infected with or affected by HIV and AIDS in particular. Not all children attend a health care centre in the company of a caregiver. The package, therefore, is designed so that it can also be used directly by a health care worker with a child and/or adolescent
- The term "health care worker" refers to all those people who are part of a health care team. Whilst the package is aimed primarily at health care work counsellors, it will be useful to all those involved with paediatric care and support. This would include nurses, doctors, home based carers and community-based treatment supporters.
- The term "caregiver" refers to the people (usually adults) who assume the responsibility of looking after children.
- The term "child" is used to refer to all young people. Throughout the package the specific needs of children of different age groups will be highlighted.

How to use this package

- The package is designed to offer health care workers

relevant psychosocial background information.

- The guiding principles and essential background information will be presented in the first few chapters. These include an introduction to concepts such as Psychosocial Care and Support (PSS), the implications of the different phases of child development for working with children and the health care team approach. These chapters discuss different ways of working with children and caregivers. They aim further to deepen understanding of the needs of children and caregivers.
- Chapter 4 addresses ways in which a health care worker can facilitate effective treatment with children and caregivers. It focuses on the biomedical experience of treatment, Voluntary Counselling and Testing (VCT), Disclosure and Adherence.
- A notable feature of this package is a set of removable Theory to Practice and check-list cards that are available at the back of the package for health care workers to use in direct contact situations with caregivers and/or children.
- The Theory to Practice cards are designed to help the health care worker transfer skills and knowledge to caregivers in order to assist them in responding to the psychosocial needs of the children in their care.
- The Theory to Practice cards highlight and make quickly accessible the most essential information, guidelines and steps for practice contained in the chapters. The book's content is translated into practical steps for health care workers, hence the title from Theory to

Practice. Although the Theory to Practice cards can be used independently of the book, they will be most effective when used in conjunction with it. The Theory to Practice card for each section is also included at the end of each chapter.

- The Theory to Practice cards consist of:
 - A generic method card which outlines the general process of how to talk about something difficult with a child. This card follows a logical step-by-step approach, with a beginning, middle and end. It was thought that it would be more helpful to design a generic card rather than work out a specific one for each situation. The overall theme concerns talking about a sensitive subject.
 - A generic method card which outlines the general process of how to set up and facilitate a support group for caregivers and/or children
 - A series of topic cards comprising five sections. These consist of background, objectives, key terms (where necessary), key actions (involving practical ways of responding to children and caregivers) and a list of key resources. These resources include relevant psychosocial tools to be used at individual, group and community levels.
- It is important that the Theory to Practice cards are not seen as a substitute for training. They will be most

effective in the hands of a health care worker who has received training in PSS care and support and counselling skills.

- The check-lists are designed to assist health care workers to make sure that they have covered the most important aspects of the information in the other two sections of the package.
- The selected check-lists will be found at the end of the relevant chapters and in the removeable set of cards.
- It is suggested that health care workers practise using the check-lists and the Theory to Practice cards in a role-play situation before using them in a real life counselling situation.
- It is advisable that health care workers working with children and families affected by HIV and AIDS who are interested in mainstreaming PSS in paediatric HIV treatment, should first read the core content in the publication itself and where possible receive training in its use. The publication contains important background information that presents the theory of PSS in an accessible way. The next step would be to carefully read the sections entitled “From Theory to Practice” at the end of each chapter. These sections summarise the actions that need to be followed and have been extracted from the main body of the text. Finally, check-lists have been provided for use in actual counselling situations. They can be referred to easily when a health care worker is sitting with a caregiver who is caring for a child who is infected

with HIV. The health care worker can use the check-list to help prepare herself for a particular topic, such as disclosure, by following the steps in the check-list. This will also ensure that all the important aspects of the topic are covered in the session with the client.

- It is strongly recommended that health care workers receive in-depth training with regard to the topics that are covered in the package. Please see Appendix 4 for information on training packages available in South Africa. While it is best to use the whole package and to receive training in its use, it is possible for both the Theory to Practice sheets and the check-lists to be used on their own by health care workers who find the main publication too difficult to understand or who cannot receive training in its use.

Other things to know about the package

- The package is intended as a user's guide. It helps identify needs and provides information about meeting these needs. It also offers guidelines for practice. It is not intended to be prescriptive. Instead it seeks to establish important parameters for relating to children and adults.
- This package focuses on the PSS needs of children and their caregivers. The medical facts have not been included in this handbook. It is essential, however, for health care workers to familiarise themselves with the medical side of the disease. A list of medical resources has been included in the references. In addition, you will find a copy

of *You and Your Child with HIV, Living Positively* (Ramsden, N & Vawda, C. 2007) in the package. This is the most recent resource for health care workers and caregivers that provides the medical facts about HIV and AIDS. Other key resources, like the Dino cards, have also been included in the package.

- It is important to see the book and the other materials in the package as documents that are in process. They will need to be continuously updated in order to keep up with developments in the field.
- Most of the observations in the package are based on what is known about the development of children in industrialised countries. There is every reason to assume, though, that children in different settings have comparable perceptions of death at the same ages. Nevertheless, it is always important to make sure that information and insights are presented in culturally appropriate ways. Language and concepts should reflect local values as far as possible.



Chapter Two: Key Principles for Understanding the Psychosocial Needs of Children and their Caregivers

This chapter gives you several important approaches with which to understand and respond to the psychosocial needs of children infected with, or affected by HIV and AIDS. The needs of caregivers are also addressed.

I. Introduction to psychosocial care and support

Key Points:

- Psychosocial care and support is expressed through caring and nurturing relationships that communicate understanding, unconditional love, tolerance and acceptance (REPSSI 2007a: p9).
- The most important sustainable and powerful form of psychosocial support is the everyday care and support provided by households, families and friends (Richter: 2006: p5).
- All children have the right to psychosocial care and support, especially when they are faced with problems and difficulties in life.
- Children infected with and affected by HIV and AIDS have

special and additional needs. The social and psychological factors that surround the illness might provide an obstacle to meeting these needs.

- Health care workers need to understand psychosocial support in order to be able to work in the best interests of the child.
- Children are resilient and have the ability to survive adversity.
- There are ways to encourage resilience in children.

What is the aim of PSS?

The aim of Psychosocial Care and Support (PSS) is to ensure that children feel supported in every aspect of their lives (REPSSI 2007a: p72). Children ought to feel listened to, cared for, respected and appreciated for who they are. Caring support will give children opportunities to grow and meet the challenges and goals of each stage of their development in a positive and healthy way. It should also give them the strength to cope with the difficulties and challenges that they might meet in their lives.

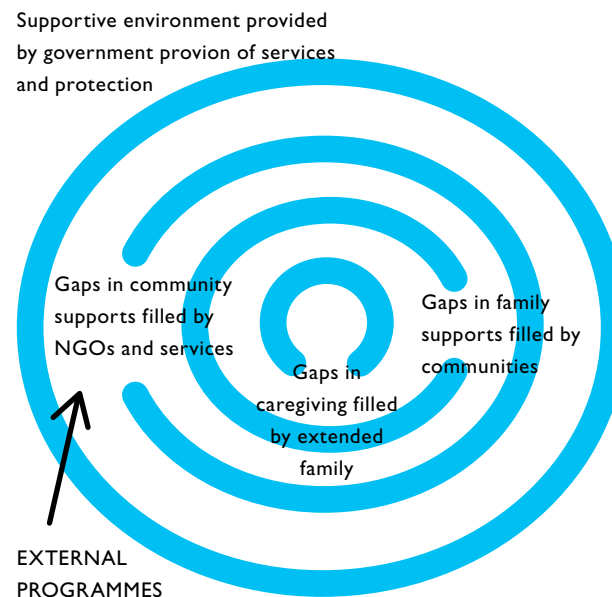
What do we mean by the term psychosocial?

The term "psychosocial" refers to the ever changing relationship between the psychological aspects of a person and the influence of his/her community/society. It implies that human beings are constantly shaped by the world around them. The psychological (psycho) aspect of the term refers to the integration of a person's mind, thinking, feelings and behaviour with the social world in which he/she lives. This social world encompasses culture, traditions, spirituality and interpersonal relationships with family, community and friends, as well as life tasks such as school or work (REPSSI 2007a: p72). The linking of the psychological and the social in the term "psychosocial" demonstrates the dynamic interaction between the two. The focus of PSS, therefore, is not just on the individual but on all of the different social units of which she/he is part, such as family, friends, and the wider community (REPSSI 2007a: p27).

What are circles of support?

A wide range of supportive relationships are potentially available to a child. These cover a spectrum of informal

and formal social interactions, from the care and support offered by caregivers, family members, friends, neighbours, teachers, religious mentors, health workers and community members to the care and support offered by specialised psychological and social services, including the health services. One way to picture this continuum is to imagine that the child is surrounded by different “circles of support”. Each of these circles offers opportunities to reinforce the wellbeing of the child. Children are best cared for by committed and affectionate adults who occupy the inner most circle of support. When the caregiving capacity of this circle is broken, extended families need to fill the gap. When the circle of care provided by relatives is broken, community initiatives need to fill the gap. When the circle of care provided by the community is broken, external agencies need to step in (Richter 2006: p18). The collective efforts of different providers of PSS can strengthen each level of the child’s “circle of support” and help prevent these circles from breaking down. In order to accomplish this, there may well be times when the child and his/her caregivers will require the specialised care and support of professionals.¹ The circles of support model in the following diagram offers good diagrammatic representation of the full continuum of psychosocial care and support.



The circles of support model

Source: Richter, L., Foster, G. & Sherr, L. (2006) *Where the Heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*.

The psychosocial impact of HIV and AIDS

There are several reasons why caregivers might not recognise children’s psychosocial needs (Stein 2003: p18). One reason might be linked to an adult’s own fear of talking about sensitive topics such as sex, illness and death. It is often easier to focus on material and physical needs at the expense of emotional and psychological needs. This is quite common in a formal medical setting. It must always be remembered that HIV and AIDS is not just a medical condition. Children who are infected with HIV do not only confront the physical effects of HIV and AIDS; they also face a range of complex psychosocial needs. This is true also of those children who are not infected themselves but who come into contact with family members and friends who are infected. The challenges facing infected and affected children might include:

- experiencing chronic ill health, pain and discomfort themselves and/or witnessing a loved one’s suffering;
- feeling uncomfortable about sharing their distress due to the stigma surrounding HIV and AIDS. This will result in feelings of isolation;
- bereavement and its consequences. These might include separation from close family members and changes in socio-economic circumstances. Such circumstances might entail having to leave school in order to find a job or look after younger siblings. Extreme forms of deprivation, such

¹ Richter, L., Foster G. & Sher, L. (2006), *Where the Heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*.

as the loss of basic necessities and homelessness, can follow from the loss of a breadwinner (ANECCA 2006: p203);

- the death of a parent. Feelings of guilt, anger, sadness and depression often accompany this experience, and need to be acknowledged and processed;
- asking questions that are either not answered at all or answered in an evasive or inappropriate way;
- a poor sense of identity and low self esteem, the consequences of the feelings of guilt and isolation that is produced by having a taboo illness;
- behavioural problems that develop as a result of not always being able to express feelings. Children may act out these feelings by being aggressive, withdrawn or drinking alcohol, for example.

Understanding resilience in children

Some children cope quite well with difficulties, whereas others are overwhelmed by them. A child's ability to cope seems to have much to do with their reservoirs of resilience. Researchers have defined resilience as the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life and the ability to bounce back after stressful and potentially traumatising events (Mallman 2002: p2). The ability to cope with adversity is related to the child's capacity to:

- understand a painful event (for example, the death of a parent);



- believe that they can cope with a crisis because they know that they have some control over what happens;
- give deeper meaning to the event.

The development of these three capabilities needs to be encouraged at every opportunity. Children are influenced as much by their inner resources as by external sources of support. There are some basic factors which promote the development of resilience in children. Most of these have to do with the quality and consistency of the parenting/ care giving that the child receives. It is important to create loving, trusting and respectful relationships with children. They should be encouraged to share and talk about their feelings. They must be allowed to make mistakes and learn from them. Children should be seen as complex and multi-faceted individuals rather than in terms of what they can and cannot do. Children benefit from growing up in a safe

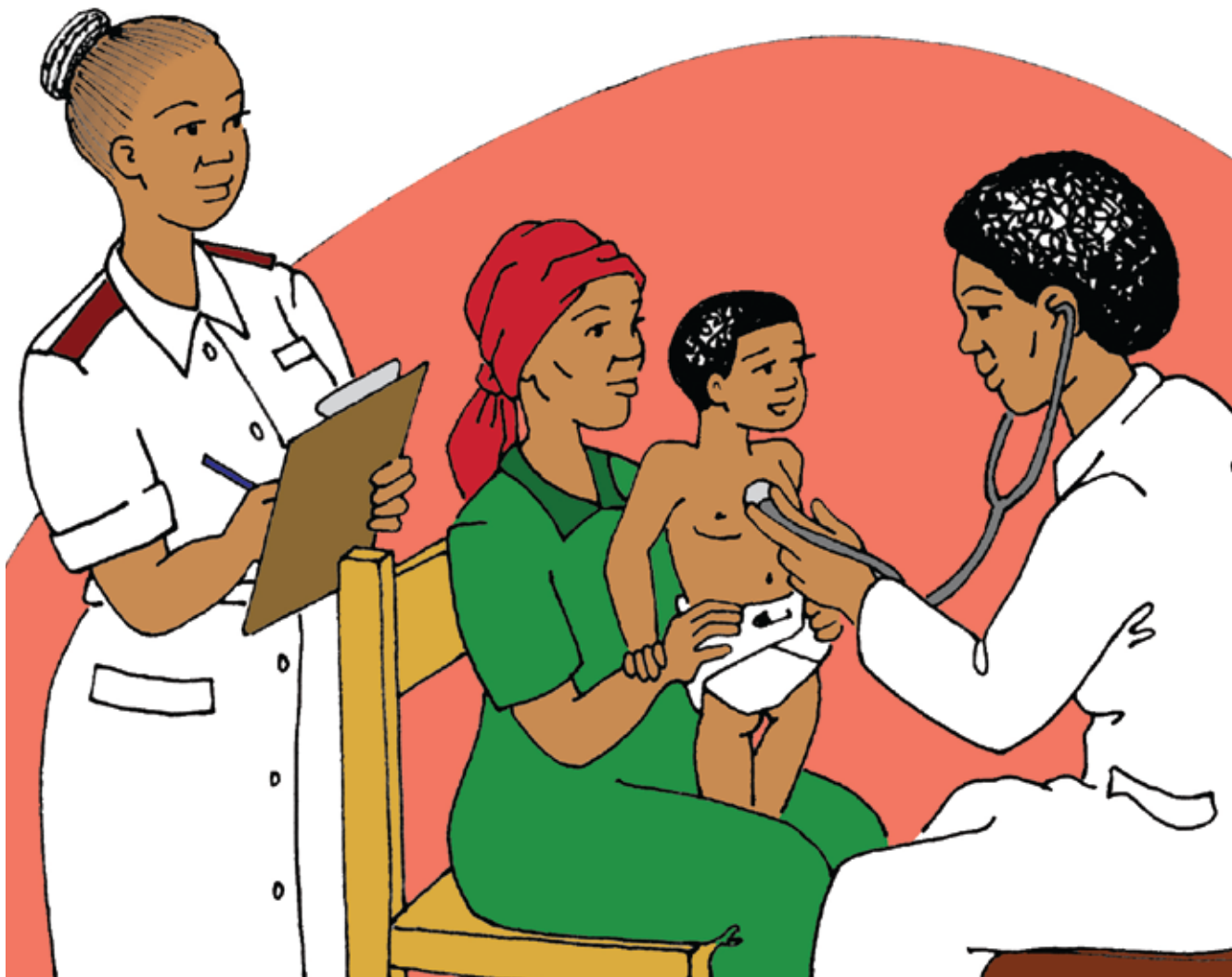
and nurturing space. They thrive on routine and family time.

The strength of a child's inner resources and access to resilience manifests itself in a number of ways. These include:

- the ability to experience and express a wide range of emotions;
- the ability to recall many of the significant feelings, thoughts, and experiences in their lives – this gives them the capacity to emotionally recall and hold onto positive memories;
- a sense of belonging – this includes the feeling of being connected to other people in a context of mutual support and care;
- the capacity to take an interest in others.

The circles of support surrounding the child, also known as external resources, need to be available in a consistent and loving way. Important aspects of external and internal support include:

- a close and secure relationship with a caregiver;
- a close relationship with other family members;
- access to food, shelter, clothing, education and medical services;
- financial stability;
- close links to a cultural/religious community;
- empathy and concern for others;
- a belief system that gives the child an idea of right or wrong and a sense of faith or affiliation to a set of values or to a religion;



- creativity and curiosity. Resilient children are open and eager to learn. They are able to use their imaginations and solve problems;
- self confidence. Resilient children have a sense of humour and like themselves (Mallman 2002: p3–5).

Health care workers need to help children strengthen their inner resources as much as they need to help build and strengthen the different circles of support that are available to children.

2. Introduction to health care team approach

Key Points

- The primary focus for the health care team is to reduce the physical and the psychosocial stress experienced by the child and caregiver as a result of HIV and AIDS.
- The health care team, through their educative and supportive role, can assist children and caregivers make choices and decisions that will prolong and improve the quality of their lives.
- The partnership between the health care worker, the child and caregiver should be collaborative.
- Open and good communication amongst health care workers lays a foundation for a strong and effective health care team.

The role of the health care team

The health care team is made up of a diverse team of professionals and, sometimes, volunteers who work together in order to improve the quality of care and treatment for the child and his/her caregiver. Each person should play a specific and clearly defined role in the overall work of the health care team. There needs to be clear communication between the members of the team at all times. This will have a positive and immediate impact on the child/caregiver; their confidence and trust in the health care team will grow. It is best if the child and his/her caregiver can always be seen by the same health care worker as this facilitates the development of a relationship and builds trust. Although the different members of the health care team have different roles, all members of the team are likely to interact with the child and his/her family at some point in the care and treatment process. It is worth noting that no matter how brief or rushed the interaction may be, there is always an opportunity to practice the values of PSS. These include respect, interest, care and inviting participation in decision making. It is also critical to view the child in the context of their circles of support. They are members of a household and community. The health care team needs to identify ways in which the child's support networks can be strengthened in order to assist the child in coping with his/her illness.(ANECCA 2006: p201).



Psychosocial interviewing

It is vital to see the child as a whole person, not just someone with a particular health problem. This will help the health care worker to understand the pressures facing the child that may be affecting his/her health and treatment.

In cases in which children are under the age of 12², the health care worker will usually communicate as much with their caregivers as with the children themselves. There will be situations, though, in which the health care worker will communicate primarily with the child. This is especially likely in the case of adolescents. Health care workers will need to establish a good rapport with adolescents if they are going to ask them meaningful questions. Adolescents need to know

why they are being asked certain questions; they do not like to feel as though their privacy is being violated. They are more likely to answer questions openly and honestly if a confidential and respectful relationship has been established between them and the health care worker. Home, school, relationships and self-perception are important parts of adolescent lives. Understanding these aspects of their lives will help health care workers to understand the adolescents themselves better. Effective ways of engaging children and adolescents will be addressed at length in Chapter 3.

Asking suitable questions can be a valuable technique when working directly with children and adolescents. The questions that follow have been adapted from the HEADSS Psychosocial Assessment tool. This was designed to assist General Practitioners to work with young people and their families while addressing the developmental, cultural and environmental factors that influence their health status (Chown & Kang 2004: p3).

I. Explore home situation, family life, relationships and stability

- Where do you live? Who lives at home with you?
- What is the atmosphere like at home? (calm; conflict; etc.)
- How do you get along with the other members of your family (or others living at home)?

² According to the Centre for Child Law (Department of Social Development 2005), legislation now in force allows a child to give consent for HIV testing from 12 years of age.



- Who could you go to if you needed help with a problem?

2. Explore sense of belonging at school/work and relationships with teachers/peers/workmates; changes in performance

- What do you like/ not like about school (work)? What are you good at/ not good at?
- How do you get along with teachers /other students / workmates?
- What problems do you experience at school?

3. Explore how they look after themselves: eating and sleeping patterns

- What do you usually eat for breakfast/lunch/dinner?
- Sometimes when people are stressed they can over-eat or under-eat. Do you ever find yourself doing either of these?
- What time do you go to sleep? Do you feel as though you have slept enough when you wake up?

4. Explore their social and interpersonal relationships, risk-taking behaviour, as well as their attitudes about themselves

- What sort of things do you like doing?
- Who are your main friends (at school/out of school)?

Psychosocial Support (PSS) Guidelines for working with children and their caregivers

A number of different options are available to the Health Care Team for meeting the needs of children and caregivers. One possible approach is to engage in a one to one counselling interview with either the child or the caregiver. Another option is to set up an in-depth interview with the child and the caregiver together. Some counsellors are also able to run support group sessions for either the children or their caregivers. No matter what form the interactions take, the following guidelines, adapted from REPSSI (2007a: pp21–22), should characterise the effective delivery of PSS:

- Respect for the rights of clients: The right of children and their caregivers to privacy and confidentiality must be honoured. The child and his/her caregiver have the right to be heard and to participate in decisions which may affect them. This means treating children and their family members as active partners rather than as the passive recipients of a service.
- Awareness of development factors: health care workers need to know which internal and external resources are present in the child's life and how these impact on the child's developmental milestones.
- Awareness of the uniqueness of each child: It is important to develop a sense of who the child is, his/her views, perceptions, ability to cope, psychosocial state and needs,

as well as his/her ability to determine and meet those needs. No two people are the same, even when they are at the same stage of development.

- Discovery of the actual and potential resources that are available to children, caregivers and communities in general. Children's natural resilience can be strengthened by drawing on the different circles of support that surround them.
- Joint planning and decision making: It is essential to establish goals by working closely with children and their caregivers. Their full participation will result in a higher degree of commitment. Both children and caregivers need to feel that their ideas and strengths have been recognised. This is particularly important when working with adolescents.
- Respect for local norms and practices: It is vital to be aware of the cultural world that children and caregivers inhabit. There will be helpful beliefs, rituals and insights that they could draw on in difficult times. There might also be harmful beliefs and practices that the health care worker might have to discuss with them in a way that is not judgemental or dismissive.
- Reflection and ongoing evaluation: This is essential. It should include the participation of both the child and his/her caregiver and colleagues in the health care team. The evaluation needs to
 - assess whether the PSS plan is working
 - identify its positive effects

- determine what is not working and find ways to correct this
- plan for the future.

The health care service also needs to assess its ability to meet the needs of its clients. This is particularly relevant when addressing the needs of young people. Values such as openness, tolerance and respect are important to young people. They do not want to feel judged.

Caring for the health care worker

Working in the field of paediatric HIV and AIDS treatment and care is emotionally demanding since it involves working with some of the most vulnerable groups in society, babies and children. Health care workers encounter serious illness and death in the course of their work. This sometimes leads to compassion fatigue or “bereavement overload” (Wienarski 2004: p134). It is essential, therefore, that health care workers receive support. Supervision sessions are beneficial. A process of debriefing³ health care workers can help relieve the emotional weight they carry. The creation of formal or informal support groups is also important. The creation of opportunities and structures that facilitate peer mentorship⁴ for the members of the Health Care Team become especially important in the case of those health care settings in which

supervisory support is not available. Good communication systems need to be put in place in order to foster a culture of recognition and empathy amongst health care workers. Ongoing professional development programmes also help health care workers cope with the stresses and demands of their work.

3. Introduction to child development

Key Points

- Understanding child development can help health care workers promote a better and more sensitive attitude towards children because it contributes to an appreciation of their needs. This will enhance holistic care, which, in turn, will improve adherence to treatment programmes.
- Each child is unique. The rate, nature and quality of development of a child are influenced by a number of factors including the temperament of the child and the nature of his/her caregivers, environment and culture.
- Children have different needs at different ages.
- Health care workers need to understand child development. This is a necessary point of reference from which to assess a child’s general sense of wellbeing.
- It is important to be able to identify when a child is in

distress and in need of specialised care.

- There are different beliefs about child development and child care.

Understanding child development

Working with children is different from working with adults. Children are in the process of going through significant changes on a number of different levels. The term “holistic” development describes the “ongoing process of growth that starts from the moment children are conceived and continues until they reach adulthood. It includes the intellectual, emotional, spiritual, social and physical development of children and is concerned with helping them reach their greatest potential. Emotional, intellectual and social development are the most important aspects of psychosocial wellbeing” (REPSSI 2007a: p13).

Development may appear to follow a linear path. It is, however, an unpredictable and dynamic process. It is constantly being influenced by life events. HIV and AIDS can cause delays in the development of physical and intellectual abilities. In addition, the experience of having a chronic illness may also affect a child’s sense of self. Thinking about development in terms of stages provides helpful guidelines to both health care workers and caregivers for dealing with the

³ Debriefing is used to reduce the possibility of emotional harm that attends working with people who have suffered loss, for example. A health care worker feels less overwhelmed by such an experience if the experience can be discussed with others.

⁴ Peer Mentorship is the process of nurturing, supporting and building counsellors so that they are able to offer the best service possible to clients while staying motivated and enthusiastic about their work. (Brouard et al. 2008: p13).

challenges that HIV and AIDS poses for the development of children. It is helpful to:

- know what can be expected of children of different ages and stages of development. This can help health care workers and caregivers respond more constructively to them;
- understand the child's routine and needs. This will assist in the process of drawing up an adherence plan;
- be aware of signs of possible developmental delay or disability. If such signs are evident, the child should be referred for professional assessment;
- understand the child's perceptions of the world. This is particularly important when working out how one should talk about sensitive issues such as illness and death;
- know the best approach for talking to and/or counselling children of different ages. A 3 year-old will need a very different approach from an adolescent.

Psychosocial development of children

There are many ways to understand how children develop and grow as they move through the cycle of life. We have included an outline of the key psychosocial tasks facing each age group, from babies to adolescents (see Appendix One entitled Outline of Developmental Stages from Birth to Adolescence). This outline can be used to help health care workers and caregivers identify, normalise, and respond to the needs of the children in their care. Children living with HIV need to be seen first and foremost as children. These children should not be

defined primarily by their illness but by the experiences and tasks that they face, according to their stage of development.

An understanding of the different stages of development should give caregivers more insight into the experiences and needs of their children. It will also help them understand some of the reasons for their children's misbehaviour or self-destructive tendencies. This might, in some cases, take the form of non adherence to medical treatment.

Satisfying these needs

A child whose basic needs have not been met will continue to express these needs in a variety of ways. Children are not always able to verbalise their needs and often express them indirectly through their behaviour. This is known as "acting out". A child who is hungry, tired, ill, bored, insecure or over-stimulated will show a marked change in behaviour. Children living with HIV and AIDS face the challenge of being HIV positive, over and above the ordinary challenges of growing up. Caregivers need to respond to the child's need to cope with a chronic and life-threatening condition while also providing the usual guidance that children need as they grow up. They have to judge whether a change in a child's behaviour is the result of normal development or a direct effect of HIV infection. Caregivers should be encouraged to discuss any changes that they notice in a child's behaviour with the health care worker.



In order to help children achieve psychosocial wellbeing and optimal mental health, we need to:

- know when their psychosocial (mental and social) development is under stress or off track and how to protect it and get it back on track;
- ensure that children are receiving not only loving and continuous care but also effective guidance for mental and social problems;

- ensure that their social environment is capable of compensating for deficiencies in their psychosocial development. The nature of the support received at home, school and religious organisation as well as in the broader community is critical. (Adapted from Robertson 2008: presentation,)

Children under stress

It is expected that children infected with and affected by HIV will experience stress.

The experience of stress strengthens some children's resilience. For many children, however, the ability to cope with the day-to-day difficulties and challenges associated with living with HIV become overwhelming. This can lead to the development of mental health problems. This means that a child will be noticeably affected in some aspect of his or her psychosocial wellbeing.

Children might start showing some of the following symptoms:

- difficulties in forming relationships
- loss of hope
- worrying, fear of loss of family, food
- low self esteem
- sadness, guilt, anger, blaming and hurting others
- withdrawal, hyperactivity, aggressiveness
- reckless or irresponsible behaviour, misuse of alcohol
- developmental problems in young children such as feeding



and sleeping problems; learning problems in older children and difficulties during adolescence. (from Robertson 2008: presentation.)

It is important for the caregiver to observe and notice any negative changes in the child. If these changes last for long periods of time, the health care worker will need to encourage the caregiver to seek professional help from either a social worker, psychologist or psychiatrist.

It is helpful for the caregiver to remember that the problem is separate in some way from the child. This helps the child to believe that the problem can be fixed (REPSSI 2007a: p64).

Understanding misbehaviour

Children need to feel that they belong, and that they are loved and accepted by the people who are important to them: parents, teachers, peers, etc. They will only feel this way when the following qualities characterise the interactions between the important adult/s in their lives and themselves:

- an attitude of mutual respect and trust
- concern and empathy
- interest and care
- recognition of their positive abilities
- recognition of their needs
- encouragement of their autonomy and independence.

(Adapted from Parent Centre 2007)

The child will reveal that these qualities are lacking by the way he/she behaves. He/she will gain a sense of belonging and importance in negative ways by drawing the parents/ caregivers into negative relationships. For example, the child who throws a tantrum receives attention from his parents. By responding to his/her tantrum, the parents inadvertently reinforce the behaviour. The long-term relationship between the child and adult can be badly damaged in the process. Misbehaviour is often a child's expression of distress and a call for help. Rather than needing to be punished, misbehaviour needs to be decoded and understood.

Some of the possible reasons for misbehaviour could be:

- The child is testing limits.

- The child is tired, ill, hungry, frightened, frustrated, confused, over-stimulated or bored.
- The child is reacting to stressful circumstances such as a change in her life, a move, a new baby, a death or a divorce. (Parent Centre 2007.)

Psychosocial development and childcare beliefs

All cultures and families have specific beliefs about how children should be treated and understood. These beliefs might be stated openly or they might be hidden. The health care worker will encounter some of these beliefs when working with children and caregivers. Beliefs may impact positively or negatively on a child. They have, therefore, to be spoken about – even if this is awkward for the health care worker.

Examples of beliefs with that could impact on a child include the following:

- Babies or young children do not understand things and have no feelings.
- Young children should not talk about sexuality.
- Boys are not allowed to cry.
- It is not appropriate to talk to young children about death.

Sensitive and respectful discussion about beliefs such as these will be useful for the caregivers. Such an approach will enable them to decide when and how to make changes to practices that have been generated by such beliefs. They are

unlikely to respond constructively if they feel criticised and exposed for their attitudes and beliefs. It is also important for health care workers to examine their own beliefs. They need to make sure that these beliefs do not interfere with the implementation of the principles of PSS.

3. Introduction to children's perceptions and experience of illness and loss

Key Points

- Children and their caregivers experience many losses as a result of HIV and AIDS.
- Children and their caregivers need help to deal with death and other forms of loss.
- Children of different ages and stages of development experience death differently.
- There are some typical and predictable responses and reactions to loss.
- It can be assumed that children are grieving, health care workers and caregivers need to find ways to identify the form that this grief is taking.
- Explore the myths about death and grief that might prevent children from receiving support and care.
- The health care worker can help children and caregivers come to terms with their grief and restore a sense of balance to their lives.

The experience of loss

Children infected with and affected by HIV and AIDS experience a range of different losses. Finding out that one is HIV positive, along with the implications of living with a long-term illness, bring about a sense of loss in the child and his/her caregivers. This feeling is intensified by the social stigma associated with HIV and AIDS, the feeling of being different and “contaminated”. The lack of accessible information about the condition leads to an especially pessimistic outlook and understanding of the illness. Children face other losses besides the loss of their health. These include:

- the loss of health and vitality as a result of infection, inadequate nutrition and poor health care;
- the loss of economic support resulting from the illness and death of parents and other adults in the extended family who were previously engaged in economic support and subsistence activities;
- the loss of parents and other primary caregivers to illness and death;
- the loss of the family. Children might be parted from caregivers and siblings because of death and illness as well as mobility and migration;
- the loss of links to social institutions as a result of stigma in the community;
- withdrawal from school because of poverty and work obligations in the home (Richter 2006: p12).

While loss is a natural part of the human life cycle, it can

dominate the life of children affected by HIV and AIDS. The most dramatic and obvious loss is that of a parent or loved one. The loss of a strong emotional attachment for both children and adults knocks them off balance. The need to restore this balance and bring things back to normal becomes essential. Grieving is a natural response to dealing with loss. In many instances, it will follow its natural course without the need for specialised attention. This process can, however, become complicated by intensified feelings of loss, unresolved feelings for the parent and unexpressed feelings of grief.

Obstacles to dealing with loss

Some of the obstacles that may interfere with the grieving process are connected to the conspiracy of silence that surrounds HIV and AIDS. This is exacerbated by the general discomfort about talking about illness and death in society, particularly to children. Some homes do not have a language with which to talk about death. This inability to talk about death communicates the message to the child that death is something that is unspeakable and, therefore, intolerable. There are also cultural perceptions and beliefs which strongly determine the ways in which children are included or excluded when it comes to dealing with a death. Sometimes it is assumed that children should be protected from painful experiences at all costs. It might also be assumed that children do not understand death and do not need to know what is taking place. It is important to acknowledge and confront these assumptions in a respectful manner. People need to



understand that children feel anxious, helpless and frightened when confronted by silence and secrecy in regard to death.

Common reactions to loss

The typical reactions to loss include denial, anger and disbelief. These reactions can also be understood as defences that work to help people cope with painful life situations. We use them often without being aware that this is what we are doing. It is important to understand these defences and respond appropriately to the child and/or caregiver. A caregiver might be unwilling to test her child because she is in denial about her own HIV-positive status. A mother could well be terrified of facing the reality that both she and her child might be HIV positive. Because denial prevents emotional pain (at least in the short term), health care workers are usually advised not “to burst the bubble of denial” suddenly and abruptly

(Wienarski 2004: p35). The health care worker can gradually challenge denial in the context of the caring relationship she establishes with the caregiver. Sometimes, though, denial can interfere with the need to respond immediately to an emergency or serious health condition. In such instances, it is important to act quickly, even if the caregiver is in denial. If the caregiver's denial will seriously affect the child's prognosis, then the health care worker will have to act with respect for the caregiver but with honest and clear communication. It might be helpful to remind the caregiver that children have the right to know about their health. There will also need to be ongoing emotional support for the caregiver in such a situation.

Ways in which children express grief

Children often mourn and achieve healing through behaviour and play rather than through the use of words. Some children experience depression. It is useful for the caregiver and the health care worker to be able to differentiate between sadness and depression.

Mood disorders, particularly depression, are common in children and adolescents. This is particularly true of children and adolescents who are affected by HIV and AIDS. Depressed children and adolescents may, like depressed adults, feel sad, lose interest in activities they once enjoyed and neglect their appearances. They may also have difficulty concentrating at school. The signs of depression will usually vary across the different developmental stages.

Pre-adolescent children may be irritable and bored. They might complain about physical things like headaches and stomach aches. They might exhibit anxiety about separation and suffer from phobias. Adolescents might experience suicidal thoughts. They could display symptoms such as sleeping excessively, increased appetite, rejection sensitivity and lethargy. The big difference between sadness and depression lies in the extent, severity and impact of the symptoms. The impact could include the child or adolescent's ability to function in areas like school, relationships and the maintenance of good health (Cheng & Myers 2005)

If the feelings that lie behind the depression are not addressed the depression might become a long-term problem. Caregivers will need to seek professional help in such a situation. On the whole, though, the family and close friends are the best people to support a grieving child. Children do not need to have intense moments of expression of strong feelings (catharsis). Research suggests that it is healthier to normalise feelings of sadness by talking about them in an ongoing way. The child should be encouraged to resume his/her normal life (REPSSI 2007a: p35).

It needs to be emphasised that children can come to terms with loss if they have enough time and support. They can be helped to understand what has happened and to find a way of talking about the event and the feelings it has generated.

There are specific aspects of mourning that a child needs to go through in order to reach an acceptance of the loss.

These are:

- The child accepts that the person has died and will not come back. He/she feels the pain of the feelings. If these feelings are not experienced soon after the death, they might return at a later stage in another form, such as sickness or problematic behaviour.
- The death of a parent or caregiver causes many changes in the child's world. The child needs time to adjust to these changes and to establish a new routine.
- The child has to find a new place for the deceased person in his/her emotional life and in his/her memory. There are ways to help the child build a positive memory of his/her parent and draw strength from this memory.

The course that mourning takes in children is unpredictable. Different factors might work against the child's ability to adapt to the death while others might reinforce it. Some of these factors include:

- **Shock.** Death always comes as a shock. An unexpected death is even more of a shock. Death due to a terminal illness offers opportunities for the parent and child to spend time together. Parents can plan the child's future by drawing up a will and arranging a substitute caregiver for the child. Secrecy surrounding HIV and AIDS may prevent this from taking place. A key concern for children is often: "What will happen to me?" or "Who will take care of me?"

- **The relationship between the child and a deceased person.** Emotional closeness affects the impact of the loss.
- **The availability of a surviving parent or consistent caregiver.** This person will be able to comfort the child and help him/her through the mourning process. A surviving parent, though, might be so grief-stricken themselves that they are unable to properly support the child. Drawing in other family and/or community support is vital at this point.
- **The nature of the extended family.** A loving family will provide a sense of belonging, protection and warmth whereas a family divided by conflict or affected by substance abuse or domestic violence will have a negative effect on the child.
- **Rituals connected with death.** Rituals provide meaning and promote understanding. They reinforce resilience in children. It is important for children to participate in collective expressions of sadness such as funerals. They need to feel included and experience communal solidarity. This has a strong healing effect. Rituals also often give children a sense of an afterlife, which can be very reassuring, and provide a space in which they can share their grief with others. (Mallman 2002: pp19–20)
- **Children understand death differently at different ages and stages of their development.** The developmental stage affects how a child sees death, gives meaning to death and is able to access inner and external resources while mourning.



There will be specific reactions that caregivers might encounter when caring for children who have lost one of more of their parents. These include clinging behaviour, sleeping difficulties, nightmares and terrors, bed wetting, intrusive memories (also called flashbacks), aggression, auto aggression, hyperactivity, magical thinking, feelings of helplessness and body pains (Mallman 2002: p47).

Once the source of a child's distress has been understood, it is possible to help them with these symptoms. There are also simple but effective ways of helping children work through their feelings. Some of these are described in the case studies that are provided below. For more information about specific reactions and responses, refer to Building Resilience, Mallman 2002.

1. Clinging behaviour

Case Study: Nangula is 4 years old. Her mother died two months ago. Nangula has never met her father. Nangula and her siblings live with her 70 year-old grandmother. Whenever Nangula is separated from her grandmother she starts to cry. She does not play with other children but tries to stay near her grandmother. At night she sleeps with her grandmother.

Clinging behaviour is usually linked to a fear of separation. The child fears that the caregiver might leave him/her just as the parent left her. Depending on the child's age, he/she might not understand that the separation is temporary.

Some helpful steps for caregivers to help children who display signs of separation anxiety include:

- Find out when and why the child does not want you (the caregiver) to leave.
- Allow the child to cling to you for some time before you leave, reassure her that you will be back and try not to be away for a long time. You will need to prepare her for the times when you are away, tell her where you are going and when you will be back. Relate it to practical events that the child can understand, i.e. after lunch, before your bath.
- If there is enough space, encourage the child to sleep on his/her own next to your bed. Let him/her take a soft toy animal to bed. Find an appropriate ritual such as prayer, storytelling or singing songs to use at bed time.
- Play games with her to reinforce the fact that people and objects can come back after they have disappeared. Suitable games include hide and seek with objects or other children and memory games. (See Mallman 2002: p49.)

2. Sleeping difficulties

Case Study: Rebecca is 5 years old. She lives with her siblings. Her eldest sister of 17 looks after all of them. Both her parents have died. At night, Rebecca refuses to go to bed. She stays awake as long as she can before falling asleep somewhere in the house.

There might be several reasons for a child not wanting to

go to bed. She might not be tired enough or be frightened of nightmares. She might fear the dark or separation from her caregiver (in this case her older sister). It is interesting to note that the language that is used to talk about death can contribute to a child's fear of sleep. Explanations such as: "Mummy went to sleep [death] or "The angels came and took Mummy last night" establish an association between death and sleep.

Some of the things you (the caregiver) need to do to help this situation:

- identify the reasons for the child refusing to go to sleep;
- find a quiet, comfortable place for her to sleep in. Assure her that she will be safe during the night. Give her a warm bath in the evening, if possible;
- have a bed-time ritual (see clinging behaviour);
- try not to blame or punish the child for her behaviour. Even if you have to let the child cry, still go into the room and let her know that you are there.

3. Nightmares

Case Study: Manuel is 6 years old. Since his mother died he has been living with his neighbours. He often wakes up in the middle of the night and cries. He dreams that someone has died and that the house is on fire.

Many children have nightmares. These are usually related to something that the child is afraid of or something that has

happened. The frightening event in the dream might take a different form from what happened in real life.

Some of the things you (the caregiver) can do to help this situation:

- it is important for you to understand what the nightmare is related to – remember that the frightening thing in the dream might be based on an imagined fear rather than something that has happened;
- comfort him when he awakes and tell him it was only a bad dream. Assure him that you are with him and that he is safe;
- help him separate his dream from reality. Remind him that his bedroom is normal and safe. Ask him what he likes in the room before asking about the dream;
- remind him about the dream during the day and talk about it. You can also discuss his fears with him in the day. This might help reduce the frequency of nightmares at night.

Theory to Practice Card Number One: Foundations of psychosocial wellbeing

1. Background

Providing paediatric HIV and AIDS treatment to children living with HIV goes far beyond doctors or health care workers dispensing medicine. The child's survival and wellbeing will depend not only on what the health care team do, but how they do it. Doctors themselves are well aware of this aspect of treatment when they refer to "bedside manner". However the most important providers of sustainable psychosocial support are parents and caregivers in the home and in the immediate community. This card highlights how health care workers can begin to support caregivers in building children's psychosocial wellbeing and resilience on a daily basis. This would go a long way to ensuring that the biomedical treatment that is offered will have the best possible results.

2. Objectives

- To support health care workers to support caregivers to lay a foundation for the psychosocial wellbeing of children in their care
- To offer ways of making children feel worthwhile.

3. Key terms:

3.1 Psychosocial wellbeing:

- Psychosocial wellbeing is consistent with the African concept of "ubuntu" – "I am, because we are, and

we are, because I am". A person with ubuntu is open and available to others, affirming of others, does not feel threatened that others are able and good, for he or she has a proper self-assurance that comes from knowing that he or she belongs in a greater whole. (Tutu 1999)

3.2 Resilience:

- The human capacity to face, overcome and be strengthened by or even transformed by the adversities of life
- the ability to bend but not break
- the ability to bounce back after stressful and potentially traumatising events. (REPSI 2007a: p45)

4. Key actions for health care workers and caregivers:

- **PSS begins at home:** Health care workers and caregivers need to be aware of the importance of having loving, kind and caring relationship with their own children.
- **Respect children:** Give children lots of opportunities to express their thoughts, ideas and wishes.
- **Positive reinforcement:** Give children encouragement wherever possible. Harsh criticism of their drawing, writing and counting, for example, is undermining and damages

their resilience. If a child has done something right, acknowledge it. If he has done something that you do not like, you need to tell him why you do not like it, so that he understands.

- Taking part in an activity which the child has chosen. When you do this, she learns that her wishes are important to you. This will help her feel important and build self-esteem.
- Show through your words and actions that the child is loved. Verbal and physical expressions of affection reinforce a person's sense of their own value. for example, hugging and holding
- Make routine times special, fun and enjoyable. Bath, bed and mealtimes offer opportunities for spending enjoyable time with the child. Read to the child, tell him stories and tell him about the things he did when he was younger. Talk about the nice things you did together during the day. This ends the day on a positive note.
- Take time to listen when he has a problem. This will make him feel worthwhile and special.
- Take an interest in his activities and hobbies. Try and attend parent meetings at school, sports events, etc.
- Make working together on chores in the house fun. This is especially useful for those caregivers who work all day and have very little time to spend with children. While

doing the dishes you could, for example, encourage the child to dry them or play a word game by asking questions like: “Who can spot an item starting with the letter A?” Children enjoy this. Ask them about their day at school while you are busy cooking or cleaning. You can let little children play alongside you while you are busy with chores in which they cannot be involved.

- **Make regular time to have fun together as a family/ household.** There are many things that families can do together. These things unite the family and give children strength and self-confidence. Outdoor activities such as sport and walking are especially healthy and important. Attending social gatherings and religious meetings as a family or household also help the child feel included and confident. Indoor activities such as games, watching TV and listening to the radio together also help bind a family. Responses to television or radio programmes can provide an opportunity to discuss crucial issues such as sex, violence, drugs and war, as well as to affirm certain values.
- **Communication:** Talk to children about many different things. This will make it easier to communicate with them when you need to discuss something important with them.
- **Storytelling:** Children love listening to stories. You can make up your own stories. Tell stories about the children themselves. This helps strengthen their sense of identity. You can also use stories to explore themes that are related to their illness such as loss, grief and the importance of closeness. It is good to encourage children

to tell their own stories.

- **Reading books:** Books help children learn about themselves and about the world. They learn to think and to ask and answer questions by reading books.
- **Body talk awareness activities:** Looking at themselves in the mirror, for example, may teach them important information about their bodies
- **Singing:** Singing is a powerful way to bring harmony and inspiration into a child's life. It also helps them to locate themselves culturally, a deep source of resilience.
- **Playing:** Playing with other children is one of the most important ways in which children learn emotional, cognitive and social skills. The friendships they develop through play are essential to their sense of self. Caregivers can sometimes direct their play by supplying them with materials such as water, sand and art materials or encouraging them to make up and present a drama.
- **Laughing:** Laughter and humour are wonderful sources of resilience.

5. Key resources

1. Mallman, S. 2002. *Building Resiliency*. Catholic Aids Action. Namibia.
 - The revised edition of this book is called *Building Resilience in Children Affected by HIV/AIDS*. It can be downloaded from the Family Health International website, www.fhi.org as well as Catholic Aids Action, www.caa.org.na.

- The book is aimed at caregivers and teachers. It supplies information and practical ideas about a wide range of topics including resilience, the impact of HIV and AIDS, children with specific reactions to loss, severe reactions and children's rights.
2. REPSSI. 2007a. *Psychosocial care and support for young children and infants in the time of HIV and Aids: a resource for programming*. REPSSI. Johannesburg.
 - This resource can be downloaded from the REPSSI website, www.repssi.org. It outlines the importance of psychosocial care and support. It also provides specific guidelines for addressing issues at family, community and household level for babies and young children.
 3. REPSSI. 2007b. *Living with X, A body mapping journey in the time of HIV/AIDS*. REPSSI. Johannesburg.
 - This resource can be downloaded from the REPSSI website, www.repssi.org. It uses an arts-based approach to take people on a body mapping journey, in which stories about oneself and one's life can be explored. It can be used in many different ways. It can be used to help people accept their HIV status, remember things from their lives and to find answers to the problems they face at present or in the future. The manual is aimed at adults but can be adapted for children.

4. REPSSI. 2007c. *Making a Hero Book*. REPSSI.

Johannesburg.

- This manual can be downloaded from the REPSSI website, www.repssi.org.
- This resource uses art, narrative and solution-focused therapies to help the child strengthen his/her resilience and his/her circles of support. The method involves inviting children to make a book in which they are the authors, illustrators and main characters. Through the process of making their books, the children have the chance to find new ways to deal with the challenges in their lives. Caregivers might want to help the children they are looking after make a hero book. They may however need some training from the health care worker.

Theory to Practice Card Number Two: Helping children deal with the loss of a loved one

1. Background

One of the most critical components of PSS that health care workers offer caregivers will be guidance about how to take the children who are in their care through the processes of death and loss. This subject requires especial sensitivity and patience on the part of health care workers and caregivers. The principles contained in this card also apply to the direct support that health care workers might themselves offer children, particularly adolescents, at a time of death or loss.

2. Objectives

- To assist the health care worker to help a caregiver to support a child who has experienced a loss/death of a loved one
- Outline general guidelines for supporting children who have experienced the loss and/or death of a loved one.

3. Key terms

3.1 Bereavement: is what happens to people as a result of losing someone or something important to them, especially the loss of a relative through death (REPSSI 2007a: p30).

3.2 Grief: the resulting mental anguish of such a loss (REPSSI 2007a: p30).

4. Key actions for health care workers and caregivers

4.1 Find ways to normalise death by explaining to bereaved children that:

- Death is a natural part of life
- Saying goodbye is part of the healing process
- Death needs to be openly and honestly discussed. Evasive and untrue explanations such as “your mommy has gone to sleep” will lead the child to expect her mother to wake up again.
- Tell children the truth when someone has died. Avoid a situation in which they learn about the death from someone else.
- Tell them that everyone dies although we do not know when someone will die. Some people die when they are old and some when they are younger. Once someone has died, they do not come back to life.
- It is normal for children to feel very sad and to worry about what will happen to them when someone dies.
- Encourage them to talk to you or to someone else whom they trust when they are sad.
- Tell them that they will always remember the person who has died in their hearts and minds.

Age of child	Understanding of Death
Birth to 3 years	Very limited understanding of what death means, although they experience the separation from that person.
3–6 years	Death is not seen as something permanent. Children grieve intensely at this age.
6–12 years	Understand that death is permanent and final. They are able to understand the causes of death.
13 years and older	Adolescents understand that death is permanent and final.

4.2 Need to give age-specific information to help children of different ages understand the concept of death

- See summary of how children of different ages understand death on page 24.
- Use age-appropriate language to talk about what has happened with the child.
- The child needs to understand that it was not his or her fault.

4.3 Maintain an ongoing loving relationship with the child

- Having a close and affectionate relationship with the remaining caregiver (this might be a parent, sibling or grandparent, for example) will help a child cope more easily with the changes in his or her life.
- Physical contact (hugging and holding) gives the child a sense of safety and security. If a child refuses to be hugged, it is important to respect his/her need for privacy,

4.4 Maintain a routine for the child

- Where possible the child should remain in his/her same home environment and follow the same routines. This might be more important than offering specific “bereavement counselling” to the child.
- Siblings should not be separated if at all possible.
- Encourage the child to play with other children and carry on with his/her day-to-day activities.



4.5 Observe changes in the child

- Notice any signs of distress or regression (for example, sleeping disorders or bed wetting).
- Make time to be with the child and try to understand and accept his/her behaviour.
- Seek help if the behaviour persists or worsens.

4.6 Keep a link with the deceased person. Young children need to remember and protect their relationships with their dead parents

- Talk about the deceased person in a natural way.
- Let the child ask questions and talk about the person.
- Encourage him/her to share good memories of the deceased person.
- Keep some of the things that will remind the child about the deceased person. These things will help the

child build a bridge between the person and him/herself.

- You can encourage the child to make sense of their experience by making a memory book or memory box. This book can become a useful store of memories and a source of comfort.
- Visit the grave with the child (if it is culturally and age appropriate).

4.7 Keep communication open

- Repetitive questioning about a parent's death may result from the child's fear that the remaining caregiver may die too. It is important (if this is the case) to reassure the child that the caregiver is not going away or going to die. You may need to reassure the child over and over again, each time this anxiety or fear is triggered. If the caregiver is not well, it is important for them to tell the child what they are doing to stay well and what will happen (i.e. who will look after the child) if the succeeding caretaker were to die.
- Answer questions that need to be answered such as:
 - How does a person die?
 - Why did the person die?
 - What happens when a person dies?
 - Did the person die because I did something wrong?
 - Will it happen to me?
 - Does dying hurt?
 - What happens to a person's body when it is buried?
 - Where do people go when they die?

4.8 Draw on your cultural beliefs and values

- It is the caregiver's task to explain religious concepts such as heaven, the ancestors and reincarnation to the child, according to the family's culture and religion.
- Pray with the child if this is part of the home culture. Children with access to a spiritual and cultural belief system are more resilient. They find it easier to give deeper meaning to loss.
- Allow children to take part in religious and traditional rituals after the death. Attending the funeral, for example, helps the child to understand what has happened. This understanding will increase his/her ability to cope.
- Children need to be involved in funeral arrangements from the start so that they can understand the whole process up until the time that the deceased is buried

5. Key Resources

1. Denise, P. 2005. *Never Too Small to Remember*. Cluster Publications. Pietermaritzburg.

- This book describes the memory work that has been done with children by the Sinomlando Centre, KwaZulu Natal, with HIV and AIDS affected families in KwaZulu Natal.

2. Mallman, S. 2002. *Building Resiliency Among Children affected by HIV/AIDS*. Catholic Aids Action. Windhoek.

- The revised edition of this book is called Building

Resilience in Children Affected by HIV/AIDS. It can be downloaded from the Family Health International website, www.fhi.org as well as from the Catholic Aids Action website, www.caa.org.na. The book is aimed at caregivers and teachers. It gives information and practical ideas about a wide range of topics including resilience, the impact of HIV/AIDS, children's reactions to loss, severe reactions and children's rights.

3. REPSSI. 2008. *Memory Work Manual*. REPSSI.

Johannesburg.

- This resource can be downloaded from the REPSSI website, www.repssi.org. It explains how to use memory work in order to help people identify and reinforce the empowering parts of the stories that make up their lives. It uses narrative and art therapy methods in order to establish a safe emotional space in which to explore stories as a form of self help or group support. It is meant for caregivers rather than children themselves.

4. REPSSI. 2007b. *Tree of Life*. REPSSI. Johannesburg

- This resource can be downloaded from the REPSSI website, www.repssi.org. It is a psychosocial tool based on Narrative Therapy. It is a tool which uses the image of the tree as a metaphor to invite children to tell stories about their lives. It aims to enable children to feel stronger and more hopeful about their present

and future lives. It allows children who have been affected by HIV and AIDS, poverty and conflict to tell, hear and explore stories of loss without feeling trapped by grief.

Check-list Number One: Laying the foundation of psychosocial wellbeing

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
Why is there a need for psychosocial support?	Read the section on the psychosocial impact of HIV and AIDs and the role of the Health Care Team	<ul style="list-style-type: none"> • Help the caregiver identify the effects of HIV and AIDS in his/her life, e.g. depression or stigma • acknowledge his/her feelings 	Adapt the psychosocial interviewing tool where it is appropriate to the needs of the child	See pages 7 and 13
What is psychosocial Care and Support ?	Read the definitions of psychosocial care and support, resilience, circles of support and psychosocial wellbeing	<ul style="list-style-type: none"> • Find simple ways to talk about the definitions with the caregiver and/or the child • Highlight the importance of the caregiver's relationship with the child 	Find out who the child is closest to and encourage the child to include these people in his/her circle of support	See pages 7 and 9
How to create a circle of support?	Familiarise yourself with local networks of support in the community	<ul style="list-style-type: none"> • Identify sources of support with the caregiver • Share relevant contacts 	<ul style="list-style-type: none"> • Identify sources of support with the child • Share relevant contacts 	See pages 8 – 9
How to give psychosocial support?	Familiarise yourself with the different ways of showing care and support and use them to evaluate your own relationships	<ul style="list-style-type: none"> • Encourage the caregiver to think about ways in which he/she can support his/her child • Share ideas for strengthening the caregiver's relationship with his/her child and building the child's self esteem 	<ul style="list-style-type: none"> • Model a caring and respectful relationship with the child • Help the child identify his/her strengths 	See Theory to Practice Card 1: Foundations of Psychosocial Wellbeing
How to integrate PSS principles in the Health Care Team approach?	Read the section on PSS guidelines and familiarise yourself with the developmental milestones	<ul style="list-style-type: none"> • Keep these points in mind when you interview caregivers about their children • Encourage a collaborative partnership with the caregiver • Show interest and respect for the caregiver's culture and values • Encourage the caregiver to think about his/her child in terms of his/her developmental needs 	Remember to see the uniqueness of each child and work together with the child to help build his/her resources	<ul style="list-style-type: none"> • See pages 12 – 14 • See Appendix 1: Outline of Developmental Stages from Birth to Adolescence

TABLE CONTINUED ON NEXT PAGE

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
Ways of meeting the PSS needs of caregivers and/or children	Read the section on PSS guidelines for working with children and their caregivers as well as the section on the Psychosocial development of children	<ul style="list-style-type: none"> • Conduct an Individual interview session with the caregiver • Conduct a joint interview with the caregiver; child and other interested family members • Set up a support group 	<ul style="list-style-type: none"> • Conduct an individual interview with the child • Conduct a joint interview with the child and a supportive family member • Set up a support group 	<ul style="list-style-type: none"> • See Theory to Practice Card 1: Foundations of psychosocial wellbeing • See Theory to Practice Card Number 4: How to set up and run a self-help support group
How to care for the health care worker?	<ul style="list-style-type: none"> • Read the section on Caring for the health care worker • Identify your areas of strengths and the areas in which you need support • Set up a peer mentorship support system or seek supervision 	<ul style="list-style-type: none"> • Ensure that you do not impose your own frustrations and disappointments on the caregiver 	<p>Ensure that you do not impose your own feelings and judgements on the child</p>	<ul style="list-style-type: none"> • See Theory to Practice Card 4: How to set up and run a self-help support group • See pages 13 and 38

Check-list Number Two: How to Deal with a Child who has Experienced Loss

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
Understanding children's experiences of illness and loss	<ul style="list-style-type: none"> Read the key messages about children's' perceptions of illness and loss See section on Phases of Psychosocial Vulnerability 	<ul style="list-style-type: none"> Explore an age appropriate response to supporting his/her child with the caregiver Anticipate the caregiver's vulnerability with regard to his/her child's HIV positive status 	Explore with the child his/her particular questions in relation to illness and loss in an age-appropriate manner	<ul style="list-style-type: none"> See page 16 See Theory to Practice Card 2: Helping children deal with the loss of a loved one
What are the obstacles that might prevent children from dealing with loss?	<ul style="list-style-type: none"> Read the section on obstacles to dealing with loss Be aware of your own responses to illness and loss and on communicating with young children, with adolescents and with caregivers 	<ul style="list-style-type: none"> Acknowledge the effects of stigma on the caregiver (loss of support and/or fear of talking to a child about illness or death) Acknowledge the caregiver's attitudes and help him/her find ways to support the child 	<ul style="list-style-type: none"> Encourage the child to ask questions Allow the child to share uncomfortable feelings (fear, sadness, anger, for example) 	See page 17
What are common reactions to loss?	Read the section on common reactions to loss and communicating with young children and adolescents	<ul style="list-style-type: none"> Explore the child's reactions to loss with the caregiver Encourage the caregiver to observe and notice any changes in the child's behaviour 	Create opportunities for the child to express him/herself using appropriate methods	See pages 17 and 18
How do children express grief?	<ul style="list-style-type: none"> Read the section on the ways in which children express grief and communicating with young children and adolescents Find the language and sensitivity to talk about illness and loss 	<ul style="list-style-type: none"> Find out from the caregiver what he/she has observed about their child's reaction to death? Explore ways of helping the child express his/her fears, feelings and concerns Remind caregivers that he/she might need to seek further help if his/her child is not showing signs of improvement 	Create opportunities for the child to express him/herself using appropriate methods	<ul style="list-style-type: none"> See Theory to Practice Card 2: Helping children deal with the loss of a loved one See pages 17 and 18
How to talk to children about death	Read Appendix 2: Age-specific perceptions about death and select appropriate key actions for the caregiver and/or child	<ul style="list-style-type: none"> Supply specific information related to the age of the child Help the caregiver find the confidence and language to talk to the child Encourage the caregiver to maintain an ongoing loving relationship with the child 	<ul style="list-style-type: none"> Find ways to normalise death Find ways to normalise HIV and AIDS Keep communication open 	<ul style="list-style-type: none"> See Theory to Practice Card 2: Helping children deal with the loss of a loved one See Theory to Practice Card 3: How to talk to a child about a difficult topic

TABLE CONTINUED ON NEXT PAGE

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
How to talk to children about death	Read Appendix 2: Age-specific perceptions about death and select appropriate key actions for the caregiver and/or child	<ul style="list-style-type: none"> • Supply specific information related to the age of the child • Help the caregiver find the confidence and language to talk to the child • Encourage the caregiver to maintain an ongoing loving relationship with the child 	<ul style="list-style-type: none"> • Find ways to normalise death • Find ways to normalise HIV and AIDS • Keep communication open 	<ul style="list-style-type: none"> • See Theory to Practice Card 2: Helping children deal with the loss of a loved one • See Theory to Practice Card 3: How to talk to a child about a difficult topic
How to help children keep their link with the deceased person	Read the list of key resources in the Theory to Practice Card 2: Helping children deal with the loss of a loved one	Encourage the caregiver to draw from his/her cultural and/or spiritual background	Create a memory book with the child, for example	<ul style="list-style-type: none"> • See Theory to Practice Card 2: Helping children deal with the loss of a loved one

Chapter Three: Communicating with Children and Caregivers

Key Points

- Effective communication is an essential component of PSS. It is the means by which the values of care, respect, non-judgmental attitudes and empathic concern are communicated to the child and his/her family.
- Communicating is a continuous process. It begins at the moment of initial contact with the child and should continue throughout the treatment process, with both the child and the caregiver.
- It is important not to overwhelm a child/or caregiver with too much information.
- It is important to build a trusting and caring relationship with the child and caregiver.
- Confidentiality is an essential component of the relationship.
- Children of different ages will need to be related to differently. They will have different concerns, depending on their age and/or stage of treatment.
- The health care worker's role with children is to find the most appropriate ways to help them express themselves, either through talking or play.



- The health care worker needs to be aware of the ways in which their own feelings, thoughts and beliefs might affect her relationship with both the child and the caregiver.

I. Communicating with children

Good communication skills are an essential tool when working with children. In order for children to share their stories with the health care worker and their caregivers, they need to feel that the caring adult is interested, engaged, and ready to listen to what they have to say. It is important to let the child and/or caregiver know that everything that they tell you will remain confidential. Confidentiality, though, can pose special problems in communicating with children and families (Adherence Networking Group 2006: pp41–42); for example, the health care worker might be in possession of information that was supplied by one of the parties on condition that it was not revealed to the other one. This secrecy might be working against what the health care worker believes to be in the best interests of all the people concerned. The caregiver, for example, might not want to disclose the child's HIV status to him/her, despite the fact that, in the health care worker's judgement, the child is ready to hear this information. The health care worker will then need to spend time discussing the situation with the caregiver in order to help him/her arrive at a decision that is best for the child.

Effective communication with children means trying to

understand the child's thoughts and feelings and responding to them in a helpful way. The health care worker needs to understand the cultural environment in which the child lives. Every culture has distinct ways of communicating, expressing feelings and dealing with difficult circumstance. This forms part of a child's social knowledge. Communication styles also vary according to social class and urban or rural environments (Adherence Networking Group 2006: p39).

The age of the child is critical to the way in which the health care worker communicates with him/her. Younger children will need the presence of caregiver in order to feel secure. Some basic principles about working with children include:

- Build rapport with the child with him/her from the beginning. This includes greeting the child and talking about an easy, non-threatening topic with him/her.
- Meet children at their level; this might mean using creative methods to help children express their feelings
- Maintain eye contact
- Don't ask too many questions
- Create a relaxed space
- Encourage them to talk by talking about general things that interest them before going on to discuss specific issues in their personal lives
- Listen attentively
- Use correct and appropriate language and information
- Avoid false reassurances and imposing your beliefs. (SAT 2003: pp2–3)

Communicating with young children

Young children do not always have the language and awareness with which to express their feelings in words. It is helpful to engage children through using non-verbal tools such as drawing and playing. These tools can assist in opening the "windows to their inner world" (Oaklander 1988: p193). Most of these techniques encourage projection. Since our projections come from inside us, from our own experiences, from what we know and care about, they tell a lot about our sense of self. What the child expresses through his/her play can display his/her fantasies, anxieties, fears, avoidances, frustrations, attitudes, resentments, guilt, wishes, wants, needs and feelings. The health care worker can use these methods in order to:

- assess the child's wellbeing
- explore and acknowledge the child's feelings
- offer healing opportunities for the child as children naturally express themselves through play.

Caregivers can also be encouraged to use these techniques. All of these techniques can be used with both individuals or groups of children.

Some examples of these techniques are:

- **Feeling Cards** such as Dino the "dinosaur" (Loeffel, H in Manske/Löffel. 2003) (see Appendix Number 3):
- Children often find it difficult to talk about their feelings. The Dino cards can help children describe a range of different feelings.

- The 12 pictures show Dino expressing different moods and emotions: anger, fear, mistrust, sadness, wonder, etc.
- You may want to introduce the concept of the Dino Card by first asking the children if they know about Dinosaurs. You could add that they became extinct millions of years ago. Introduce each card to the children. Take more time to discuss the cards that are not self-explanatory. Once you have gone through all the cards, ask each child to give you an example of a time when he/she felt this way. For the card that represents mistrust for example, you could ask questions like the following: "Can I trust this person? Why is he or she coming to visit me now? What do they want from me? Should I go to this support group?"
- The meaning of each Dino card could be summarised as follows:
 - 1. Optimism:** The feeling you have when you are hopeful about your life and things working out well.
 - 2. Mistrust:** The feeling you have when you are not sure if you can trust a person or not.
 - 3. Anxiety:** The feeling you have when you are worried about something.
 - 4. Reflection:** The experience of thinking things through in different ways.
 - 5. Fear:** The feeling you have when you are concerned that things might not work out well.
 - 6. Happiness:** The feeling you have when you are enjoying life.
 - 7. Sadness:** The feelings you have when you experience loss and sorrow.



8. Anger: The feelings you have when you have reached your limit.

9. Contentment: The experience of feeling satisfied.

10. Assertion: The feeling you have when you are confident and know you rights.

11. Wonder: The experience of the beauty and excitement of life and the world.

12. Safety: The experience of feeling safe and protected.

Of course each card can be interpreted in different ways.

- The children could be allowed to express their own feelings. For instance, you can ask them to select a Dino picture that represents their emotions on that day.
- It is a good idea to also ask the children to act out the emotions that are represented by the different cards. This helps them to experience the feeling more directly.
- The Dino cards can also be used to define goals. The steps to achieve this are: Which Dino represents their

mood now? Which Dino would they like to be? What would be necessary to help you get closer to your favourite Dino? What can you do to come closer to this Dino? (Points developed by Madoerin, 2007)

- **Drawing.** This allows the child to communicate his/her feelings without putting them into words. It is good to give children the opportunity to use different materials, such as pencils, pens and crayons:
 - Ask them to draw something related to what you need to talk to them about, e.g. what makes you angry?
 - Ask what is happening in the drawing.
 - Always check your understanding with the child.
 - Use open questions to find out more about the drawing.
- **Story-telling.** This is an indirect way of getting children to talk about themselves. It helps them identify with other people and to feel understood. Story-telling:
 - Can be useful for problem solving
 - Can use animal characters to convey a message to child
 - Avoid using real names
 - Ask the child to talk about what happens in the story
 - Children can be encouraged to make up their own stories with leading questions such: "Tell me the story about the girl who was feeling very sad."



- **Drama.** Choose a topic with child
 - Let them act out situations.
 - Ask questions in the context of the role they are playing but also remember to debrief them after the role play. They need to be helped to step out of the role-play drama.
- **Play**
 - Involves imitating and acting out
 - Helps to give them ordinary objects, animals, people and cars

- Ask them to show you parts of their life using the toys
- Make comments to check if you have understood the meaning of the play
- If a child seems stuck, help him to continue the game by asking questions such as: "What is going to happen next?" (Adapted from SAT 2003.)

There might be specific themes which emerge through these activities. Some of these will be related to the child's age/ stage of development while others might be related to his experiences of HIV and AIDS. They might refer, for example, to their early diagnosis or the state of their health. Some of the common themes that might be expected to emerge through counselling include:

- fear of others finding out their diagnosis
- fear of rejection
- fear about their own health
- concern about their parents' health
- an inability to talk openly with their parents about dying.

Although children do not feel the same about their illnesses, some feelings are common. Denial is a frequent response to illness. Children tell themselves that everything is fine and that nothing has changed. Anger is another regular response. This can take the form of self anger and blame. It can also be directed at other people, especially those who might be seen as responsible for a child's HIV status. Hope is another natural emotion. It holds out the possibility that the child will get

better soon. While denial is a normal coping strategy, it should be replaced over time with an acceptance of the illness and a willingness to look after him/herself and take an active role in his/her treatment.

2. Communicating with adolescents

The older the child, the more maturity and knowledge he is likely to display in his relationship with the health care worker (Oaklander 1988: p291). It can take a great amount of trust and effort, though, to get the most out of the capacity of adolescents to form meaningful relationships. Many adolescents feel self-conscious, mistrustful and anxious about seeing a health care worker. Adolescents should be given the opportunity to choose whether they would like to see the health care worker in the company of their caregiver or on their own. He/she will need to be helped to express feelings of anxiety, loneliness, frustration, self-hate, sexual confusion and fear (Oaklander 1988: p291). It is important to encourage adolescents to be involved as much as possible in the decision making process and to give them a role, that is appropriate to their age, in implementing those decisions (Adherence Networking Group 2006: p44). There is a lot that adolescents can do for themselves.

It is still essential, however, to involve caregivers and other family members in your work with adolescents. This is



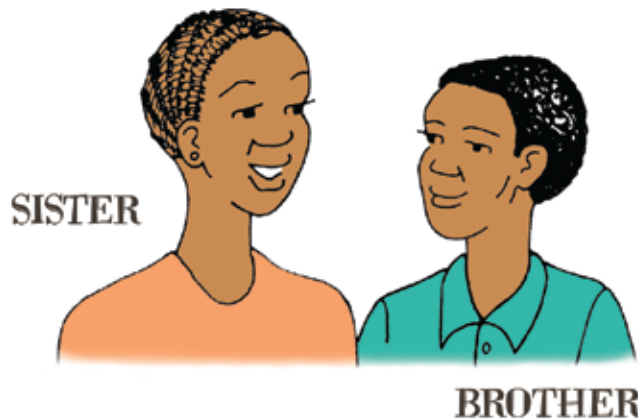
particularly true when trying to improve the communication between the adolescent and the caregiver. Caregivers sometime need help to understand that their children are separate from themselves. Adolescents need to have their independence and autonomy respected. Caregivers need to learn how to convey concerns about adolescent to them in ways that are not overprotective or undermining.

Below are some useful pointers to remember when communicating with adolescents:

- Build rapport with the person; it may take a number of sessions before you have established a relationship of trust.
- Engage and take an interest in the person themselves and not just their physical condition.
- Take a comprehensive approach: conduct a psychosocial interview to identify the broader concerns in the young person's life.
- Explain confidentiality and its limits to the young person. There are some situations in which it may be necessary to breach confidentiality. These relate mainly to the adolescent's own safety or the safety of others: if the adolescent is threatening to harm or kill himself/herself; if someone else is threatening or harming them (e.g. physical/sexual abuse); if the young person is at risk of harming someone else (Chown & Kang 2004 : p21.)
- Be yourself. Have the confidence and authority to act in ways that you know are right without being authoritarian.
- Be direct. Use clear, jargon-free language.



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HOME**



- If it is culturally appropriate, try to see the adolescent on his/her own. This gives them a sense of privacy and allows them to raise issues that they might be reluctant to talk about in the presence of a caregiver.
 - Ask permission from the adolescent before you discuss certain issues with their caregiver.
 - Use an interactive participatory style of communicating. This will include feedback, eliciting ideas, encouraging questions and explaining processes and procedures.
 - Establish an approach in which you and the adolescent engage in a dialogue. Allow the adolescent to educate and inform you e.g. "I'm not sure have I got this right?"
 - Adolescence is a time of experimenting with new forms of behaviour. The health care worker might need to provide the adolescent with relevant health related information.
- (Adapted from Chown & Kang 2004.)

There are specific concerns that adolescents living with HIV and AIDS might have. These include:

- The impact of HIV and AIDS on the physical appearance of the child/adolescent. Body image is particularly important in adolescence and is strongly linked to self-esteem. Certain medication can, for example, contribute to dermatological problems such as warts. Sick children might also be small for their age. They might struggle academically due to the cognitive impairment associated with perinatal infection.
- Dealing with stigma and discrimination from family

members and their peer group. This might, for example, take the form of parents not allowing them to eat off the same plates as other family members.

- Facing the challenges of living on his/her own (being orphaned) as a result of having lost both parents.
- Accepting their HIV status and learning how to live a positive life.
- Difficulties in sharing their HIV status with friends and family for fear of rejection and exclusion.
- Dealing with their own ill health or that of a caregiver.
- How to deal with caregivers' attitudes towards their illness, e.g. some caregivers prefer to send children to traditional healers than to the clinic for antiretroviral treatment.
- Dealing with issues of discipline with caregivers.
- Dealing with dating and relationships and having to decide if and when to disclose their HIV status to a boy/girl friend.
- HIV prevention and safe sex options. (Sibanda 2008)

Adolescents can benefit from being part of a support group. This is particularly true of orphans. A support group offers opportunities to exchange views and experiences, and breaks the isolation that accompanies the illness. HIV-positive adolescents enjoy the same activities as all young people of their age group. These include sports, recreation, drama clubs, art and craft-making. Young people can also be encouraged to become peer counsellors or peer educators. This might happen in the context of the support group to which they belong. They could also attend a peer support training programme. Peer counsellors act as role models for young

people who still need support in order to accept their status and learn how to live with HIV and AIDS.

3. Communicating with caregivers

Key Points

- Caregivers are the most important resource for children in the context of HIV and AIDS (REPSSI 2007A : p74).
- If the child's needs can be met within the home, it is not necessary to rely much on outside help.
- It is important to strengthen the relationship between the caregiver and the child.
- Children need their caregivers to help them take their medication.
- Caregivers' fears and concerns and beliefs will directly impact on the treatment of the children in their care.
- Disclosure of a child's status or of the caregiver's status to the child are probably the most difficult challenges facing a caregiver.
- Caregivers need to be able to cope with their burden of care.
- There are ways of supporting caregivers in their role of supporting children.

Who is the caregiver?

The term caregiver is used to refer to the people (usually adults) who assume the responsibility of looking after children.

Not all children live with their parents. In some cases this might be the result of the death of a parent. In the absence of the parents, the caregiver might be a relative, a friend or a person in the community who has undertaken to look after the child. Some children live with formal or informal foster parents. Some live in a children's home or shelter (Adherence Networking Group 2006: p38). Some live in child-headed households. Children may themselves be looking after younger children. Some may even be living on the streets. Caregivers exist in all these contexts. It is important to involve different people in the care of a child, even though there will need to be a primary caregiver. Ideally, more than one of the child's caregivers should be invited to some of the sessions, in order to widen support.

Although it is helpful to regard the child and the caregiver as a unit, it is essential to remember that they are separate people with different needs. The ultimate focus is on the needs of the child. The younger the child, the more dependent he/she will be on his/her caregiver. While adolescents might prefer to be seen by the health care worker on their own, it should not be forgotten that they rely on the support of caregivers and trusted allies.

The needs of the caregiver

Caregivers bring their own perceptions and needs to the health care situation. (Adherence Networking Group 2006: p38). health care workers need to respond to their needs.

They have to be supported in different ways. This will help to ensure that caregivers do not block the progress of the children who are in their care (Adherence Networking Group 2006: p38).

Common issues experienced by caregivers are:

- Inaccurate beliefs about HIV and AIDS
- Denial regarding their own HIV status
- Feeling responsible for the child's infection. This will especially be true if the caregiver is a mother who has transmitted the illness to her child (Mother to Child Transmission or MTCT). These feelings might take the form of guilt, anger, anxiety or hopelessness
- Decisions about having more children if the mother is HIV positive
- Feelings that are connected with revealing his/her own HIV status to the child
- Anxiety about their own death and future plans for their children
- Financial concerns if they are unable to work
- Feelings about disclosing the child's status to him/her, as well as to their spouse, other family members and outsiders like school authorities
- Feelings a grandparent or aunt may have about the child's deceased parents or about having to take on the responsibility of raising a child. (ANECCA 2006: p204.)

Many caregivers may be affected by housing and financial

worries, unemployment and poverty as well as by HIV and AIDS. People encounter additional stress if they do not have easy access to services. These feelings together might lead to a sense of hopelessness, which in some cases will prevent caregivers from disclosing a child's HIV status to him/her. It is necessary to acknowledge these feelings and help the caregiver understand his/her fears. The health care worker needs to weigh up the options with the caregiver so that she is in a stronger position to make important decisions on behalf of herself and her child. It is useful to emphasize the positive results that follow from a successful disclosure. Other clients' experiences can be important sources of inspiration in this regard. Meeting other caregivers, either on a one to one basis or in the context of a support group, can also be very helpful.

Support groups are vital as they:

- break the isolation of a caregiver's situation
- create opportunities for receiving support from people who are in the same situation and have overcome similar obstacles
- play an important role in encouraging caregivers to disclose to their children and other relevant people.
- offer caregivers more information about looking after themselves and their children.

Where possible, caregivers who show strength and resilience should be encouraged to set up support groups in their communities and act as role models for others.

Experience of the health care worker

Health care workers will go through many emotions when working with children and caregivers. They will sometimes experience anger and frustration. Caregivers will not always follow their advice. They will witness important information being withheld from children. They might have strong feelings of disappointment and helplessness when they see a child's health being compromised by a caregiver's reluctance to tell a child or relevant family members that the child is HIV positive. Health care workers need to recognise these feelings and find constructive ways of helping the caregiver face her fears. It is very important not to show the caregiver that she is being judged negatively. Instead, the importance of their role should always be acknowledged. It is also vital to value their observations and opinions and to keep them involved in the health care process. Let them know that their efforts will be rewarded with the love and joy that goes with rearing happy, hopeful and curious children (REPSSI 2007: p72).

It is advisable for health care workers to have a list of referral organisations that might be able to address some of the caregiver's practical concerns. Health care workers can assist caregivers to gain access to the support that is available, such as child care grants.

Theory to Practice Number Three: How to talk to children about a difficult topic

1. Background

Disclosing to or discussing with a child for the first time that he or she is HIV positive is a very difficult thing for any parent, caregiver or health care worker to do. These guidelines provide guidance around difficult conversations with children in general.

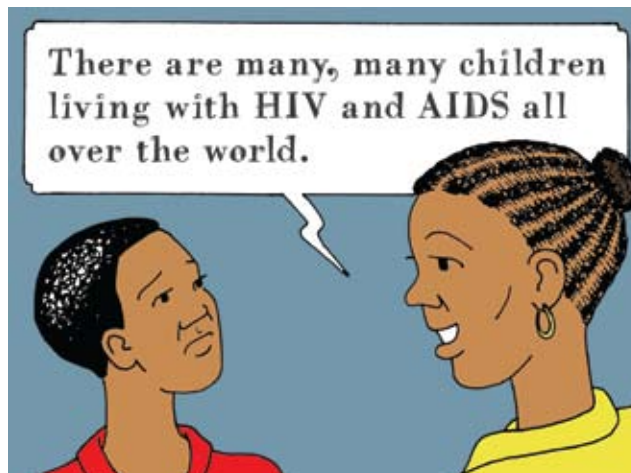
2. Objectives

- to help a health care worker assist a caregiver to talk about a difficult subject (disclosure is used as an example) to a child. This approach can also be used by the health care worker when working directly with a child. These principles also apply to health care workers' interactions with caregivers
- to offer a step-by-step approach to talking about a difficult subject.

3. Key actions for health care workers and caregivers

3.1 Knowing your child

- Caregivers have a natural love and concern for their children. They usually know what they need and how best to comfort them. This close relationship makes it possible for them to talk about difficult subjects, such as illness and death, with their children.



- Caregivers know their children best. As a caregiver you will probably have a good idea about how much your child already knows about things like HIV and health.
- If you do not know the child well enough to talk about sensitive subjects, ask somebody who is close to the child to speak to him/her

3.2 Starting a conversation with your child

Talking to a child about a sensitive subject should not be a once-off event. It should become part of the ongoing part of the relationship between you and your child. This will allow the child to trust you and know that he/she can come to you when needing information, comfort and

support. These are some of the considerations that you will have to keep in mind when starting a conversation with the child:

- Find a quiet, comfortable space in which to talk. You want the child to feel safe and comfortable and have enough time to talk properly. You need to make sure that you will not be disturbed by other people. If the child is old enough, you could ask him/her where they would like to sit.
- Prepare what you want to say to your child. You might have to find the specific information that you think you might need by speaking to other people or consulting some of the resources that are listed at the end of this cue card.
- It is important not to overwhelm the child with lots of new information. It helps to start with something general and familiar and then to move on to more difficult information, which can be shared gradually.
- It is helpful to open a difficult conversation by first talking about what the child already knows.

3.3 Sharing the facts

- Assess how much information is necessary to share with the child. You do not want to overload the child

with information that they are not ready to understand and assimilate.

- Use words that the child understands – see pages 58 and 59.
- Listen for cues from the child. He/she will ask questions. These questions need to be responded to.
- Try to know the facts yourself before the session with the child.
- If you do not know the answer to a question, tell the child that you do not know but will find out.
- Potentially damaging behaviour can result from children not knowing the facts about something. They might blame themselves or become confused and hurt. They might look for comfort in drugs and drink. They can become aggressive and distrust relationships.

3.4 Speaking about feelings

This is probably the most difficult and important part of the conversation with your child as it involves your own feelings about the subject, your protective feelings for your child, and your child's own feelings. Here are some ways to manage these different feelings:

- **Know what you are feeling yourself:** Your feelings might be very strong and complex. You need to know and understand what you are feeling. Emotions such as fear, guilt and shame can easily be transferred to the child. The child will see these feelings in your face. It might be important to get help to understand and

come to terms with your own feelings so that you can help your child

- **Notice the child's reaction to what you have shared with him.** Your assessment of this reaction will be based on what you know about how the child shows his/her feelings of anxiety, fear, confusion and anger. Expect the unexpected. The child might be in a state of shock. She might show strong feelings or appear to have no feelings at all.
- **Try to identify these feelings and respond to them appropriately.** A child who exhibits fear needs to be reassured: "It's going to be okay." A suitable response to a reaction of shame might be: "It's not your fault" or "This does not change who you are. It does not make you a lesser or worse person."
- **Acknowledge the child's feelings:** Tell him/her that there is a lot to understand and talk about. Assure the child that you will keep the conversation going and that you will always be available to talk about these issues.
- **Normalise the child's feelings:** Let the child know that his/her feelings are natural, valid and to be expected in the circumstances. If the difficult conversation involves disclosing the child's HIV-positive status, tell the child that lots of people and children also have this illness and are able to lead normal lives.
- **Comfort the child:** Children feel comforted when their feelings are understood. A child may need to be held in the same way that you would calm a distressed

baby. Comfort the child with soothing words and actions such as hugs.

3.5 Giving hope to your HIV-positive child

There are a lot of positive messages that you can give your child. This is very important as it will give your child strength and the motivation that he/she needs to keep healthy and to be able to cope with the challenges of being infected with HIV. Some of the positive things you can do or say are:

- Doctors are working all over the world to find new medicines and ways of helping people who are living with HIV.
- Having an illness does not change who you really are.
- There are many people and children living with HIV and AIDS.
- There is medicine that you can take to help you feel better.
- You can still go to school, have friends and enjoy your life.
- Create a specific goal/hope with your child that is realistic such as to learn how to play soccer or to meet new friends.

3.6 What to do next for the child after the first conversation?

This step acknowledges that your child will experience

different feelings at different times. It is reassuring for your child to know that he/she can tell you how he/she is feeling at any time and that you will work things out together.

- Stay close to your child so that you can monitor what he/she is feeling and going through.
- Start a conversation again when you think this is necessary.
- Encourage children to take the lead in telling you what they need. They might express a need, for instance, to meet other children through a support group.
- You might have to refer your child to a professional counsellor if you feel you are not coping with the child's strong reactions and if one is available. Do not be afraid to do this. You have not failed the child. It shows your concern for the child.

3.7 What to do next for the caregiver

Caring for a child who is infected with HIV and AIDS is very challenging. It will have physical, emotional and financial implications for you, the caregiver,. You will need to seek help to get as much information about HIV and AIDS as possible. It is also advisable to receive some counselling to help you sort through you own feelings, fears and concerns. Joining a support group of caregivers in a similar situation to your own can be extremely valuable.

- Receive counselling
- Join a support group
- Get more information.

4. Key Resources

1. Children's Rights Centre. 2007. *My Living Positively Handbook*. Jacana Media. Johannesburg.
 - This resource is a work book for a caregiver to use with a child who is living with HIV and AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, talking about HIV, discrimination and adherence.
 - Contact details for Children's Right Centre are: 27 31 307-6075, www.childrensrightcentre.co.za and email address: info@crc-sa.co.za .
2. Ramsden, N & Vawda, C. 2007. *You and Your Child with HIV – Living Positively*. Children's Rights Centre.
 - This book is included in this package. It is aimed at caregivers of children living with HIV and AIDS. It includes medical information related to testing, treatment, living positively and referral contacts
 - Contact details for Children's Right Centre are: 27 31 307-6075, www.childrensrightcentre.co.za and email address: info@crc-sa.co.za .
3. Soul City Publications.
 - Soul City offers a wide range of health-related booklets including topics such as HIV/AIDS, Social Grants, Health and Lifestyle issues. Booklets are aimed at young people, parents, health care workers and teachers.
 - Contact details for Soul City Distribution: 0860115000, website www.soulcity.org.za.

Theory to Practice Card Number Four: How to set up and run a self-help support group

1. Background

Support groups have important benefits for both caregivers and children living with HIV and AIDS. It is necessary to first identify the purpose of the support group in order to determine who the members of the group should include. It is possible to run support groups for different groups of people. These might be adolescents living with HIV and AIDS, young children living with HIV and AIDS or caregivers of children living with HIV and AIDS.

2. Objectives

- To help health care workers appreciate the value of a support group
- To make health care workers aware of the practical skills required for setting up support groups
- To identify key qualities for facilitators running support groups.

3. Key terms

3.1 Support group: a group of people with common concerns and needs who meet for the purpose of sharing their experiences and helping each other through difficult times (Sweetland et al. 2005: p1).

3.2 Facilitator: the person who runs a support group.



Not everyone is suited to running a support group. Training is essential and will differ depending on what type of support group is being run (Sweetland et al.2005: p1).

4. Key actions for health care workers

4.1 Understand the need for a support group

Support groups can offer the following:

- a safe place where feelings, reliable information, support and advice can be obtained and shared
- opportunities to draw strength from other people's experiences
- a reduced sense of isolation and the promotion of the acceptance of people who are HIV positive
- insight into oneself and others
- networking possibilities.

4.2 Understand the importance of a well-defined purpose for the support group and the need for confidentiality

In order for a support group to work you need to:

- Recruit people who agree to be members: this could be done through talking to doctors, nursing sisters and/or social workers. Pamphlets or posters could be used to advertise the group. Include only contact details (but not the venue and time of the meeting) if you would like to ensure anonymity. Distribute pamphlets when you think it would be appropriate. You can also recruit members through

speaking to local community leaders and non governmental organisations. You could also approach people on a one to one basis.

- Give people the choice to disclose their status and/or situation: disclosure should not be a prerequisite for membership of the group.
- Ensure that there is a common purpose among the group members: group members should decide what the aims and the activities of the group should be. The different needs of the group will determine the membership of the group. One group might, for example, comprise children living with HIV and AIDS, another might consist of caregivers of children living with HIV and AIDS while a third might be made up of adults living with HIV and AIDS.
- Nominate people to coordinate the activities of the group: this encourages participation and motivation.
- Develop a realistic programme of action for the group: the following topics could be included: disclosure, adherence, treatment literacy, stigma and advocacy. It is important to encourage members to suggest relevant topics.
- Social events: It is important to include social events in the group's activities. These bring fun and pleasure into members' lives.
- Evaluate regularly: the group members' experiences of the group and their evaluation of its ability to meet their needs have to be monitored on an ongoing basis.

- Group membership: It is best to run a group with 6–12 members. Small groups are better for building trust. The size of the group depends, though, on the purpose of the group and whether or not the group has a closed or open membership policy (is the membership restricted to the original group or can new members join at any time?) Bigger groups often offer teenagers or adults more social opportunities.
- Hold meetings at accessible and user-friendly venues.

4.3 Different types of support groups

There are many different types of groups that are useful for people affected by HIV and AIDS. Sometimes the aims of these groups will overlap. The different types are:

- Education Groups: The main aim is to supply important information about specific or common problems that affect the members' lives. Often these groups use a workshop format which involves using activities to encourage participation amongst the members. Lectures and guest speakers can be helpful.
- Peer-led groups: These groups are run by people who are themselves affected by HIV and AIDS. The main purpose of peer led groups is to provide mutual support. These groups rely on the initiative of certain individuals who assume leadership roles among their peers. Their example encourages other members to assume a more proactive stance with regard to their

own health and lives (SAT 2005. p10).

- Therapeutic Group: The main aim is to encourage conversation and discussion among members. Such a group is run by a facilitator. The facilitator is a constant presence in the group. The aim of the therapeutic group is to help bring about change in the members' lives.

4.4 Check-list for running a successful group

Please use the following points to check whether or not these have been covered.

1. Do you have a group facilitator who can build trust, keep the focus and respond to the needs and dynamics of the group? Group dynamics refers to the different ways in which people communicate, make decisions and behave within the group
2. Have you got a group contract? This is created by the group members. It sets out the aims and form of the group as well as establishing certain rules and principles for members. Standard group rules include confidentiality, punctuality, attendance, voluntary participation, mutual respect and non-judgmental attitudes.
3. Does your facilitator demonstrate the following skills:
 - Encouragement: being friendly, warm and responsive to others; praising others and their ideas; accepting the contributions of others
 - Gate-keeping: trying to make it possible for all members to make a contribution if they choose. Everyone should have a chance to be heard
 - Equal participation: accepting the decisions of the group, thoughtfully considering other people's ideas, serving as an audience during group discussion
 - Mediating: finding common ground, making compromise solutions
 - Relieving tension: draining off negative feelings by using humour appropriately, putting a tense situation in a wider context
 - Encouraging therapeutic conversations – helping members openly express their feelings and thoughts. This helps lighten their emotional load. Hearing different points of view can help members think about or change ideas that may be undermining their ability to cope
 - Information giving: offering facts or relating one's own experience to group problems to illustrate points
 - Summarising: pulling together related ideas or suggestions, restating suggestions after the group has discussed them
 - Diagnosing: determining the source of difficulties and the main blocks to progress and deciding on appropriate steps to take next.
4. Does your facilitator demonstrate the following qualities?
 - Warmth and empathy (the ability to put oneself in someone else's shoes)
 - The ability to communicate with others and to facilitate communication between people
 - A commitment to individuals affected by HIV and AIDS
 - Self awareness of his/her own values, attitudes and beliefs
 - Reliability and dependability
 - Ease, confidence and knowledge about the topics discussed.
5. Does your facilitator receive ongoing supervision and/or support from colleagues to help him/her cope with the difficulties that may arise in the group.?

5. Key Resources:

1. Sweetland, A et al: 2005, *Psychosocial Support Groups in Anti Retroviral Therapy Programmes*, World Health Organization, Switzerland.
 - This resource gives detailed information about ways of supporting people living with HIV and AIDS.
 - Contact details: www.who.int/publications

Check-list Number Three: Communicating with children/adolescents and caregivers

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
Why we focus on communication skills?	<ul style="list-style-type: none"> • Read the key points on communicating with children, adolescents and caregivers • Identify your own communication strengths • Identify the aspects of communication in which you require further training • Find out about appropriate training courses that will prepare you to communicate with young children, adolescents and caregivers 	Show respect and empathy by listening attentively and acknowledging the caregiver's needs, feelings and fears	Show respect and empathy by listening attentively and acknowledging the child's needs, feelings and fears. This helps build a trusting relationship.	<ul style="list-style-type: none"> • See page 31 • See Appendix 4: Training packages and contact details
What do we need to know about communicating with young children?	Read the section on communicating with young children	<ul style="list-style-type: none"> • Support the caregiver in strengthening his/her relationship with his/her child • Discuss the child's psychosocial challenges with the caregiver • Select appropriate tools for the caregiver to use with his/her child • Stress the importance of confidentiality 	<ul style="list-style-type: none"> • Create opportunities for the child to express his/her feelings and needs by using appropriate tools • Stress the importance of confidentiality 	<ul style="list-style-type: none"> • See Theory to Practice Card 1: Foundation of psychosocial wellbeing • See Theory to Practice Card 3: How to talk to children about a difficult topic • See pages 32-34 • See Appendix 3: Dino Feeling Cards

TABLE CONTINUED ON NEXT PAGE

Topic	Action by health care worker	Action by health care worker with Caregiver	Action by health care worker with Child	Page
What do we need to know about communicating with adolescents?	Read the section on the basic principles of communicating with adolescents	<ul style="list-style-type: none"> • Support the caregiver in strengthening his/her relationship with the adolescent in his/her care • Discuss the psychosocial challenges facing the adolescent with the caregiver • Select appropriate pointers which the caregiver might use with his/her adolescent 	<ul style="list-style-type: none"> • Create opportunities for the adolescent to express his/her feelings and needs by using appropriate tools • Encourage the adolescent to join a support group • Create a trusting relationship with the adolescent • Stress the importance of confidentiality 	<ul style="list-style-type: none"> • See pages 34-36 • See Theory to Practice Card Number 3: How to talk to children about a difficult topic
What do we need to know about communicating with caregivers?	Read the section on communicating with caregivers	<ul style="list-style-type: none"> • Show empathy for the caregiver and his/her situation • Help the caregiver identify his/her fears • Provide an ongoing trusting relationship with the caregiver • Do not impose your-own judgement and beliefs on the caregiver • Find a gentle yet direct way of confronting "denial" if it is necessary • Encourage caregivers to join support groups • Stress the concrete ways in which a caregiver can support his/her child 	Encourage the child to involve his/her caregiver or any other source of support in his/her life as much as possible	<ul style="list-style-type: none"> • See pages 37 and 50 • See Theory to Practice Card 3: How to set up and run a self-help support group.

Chapter Four: How to Facilitate Successful Treatment with Children and Caregivers

I. Biomedical experience

Key Points

- Seeking medical care is not a neutral experience.
- Patient information, knowledge sometimes referred to as treatment literacy, is vital to manage anxiety and provide effective care, irrespective of the stage of the illness.
- Health care Workers need to support caregivers with information about the medical/clinical side of dealing with HIV and AIDS.
- There are ways to reduce the stress associated with medical treatment.
- Early involvement with caregivers is a critical component of care.

First contact with the child and/or caregiver

The first contact with the child and his/her caregiver will centre on the medical/clinical details of the child's condition. Entering a clinic or hospital is not a comfortable experience for most people. Medical institutions are usually associated

with emergencies and ill health and high levels of stigma often surround HIV and AIDS. Some people feel intimidated by health care professionals. Culturally different understanding of the nature of health, diseases and treatment can also create distrust and suspicion.

The need to form open, trusting relationships with the child and his/her family is vital. It is helpful to consider the relationship as a long-term one from the start. The health care worker should use the point of entry into the health care system to begin building the relationship. It is important at this stage to set up the next visit by the child and caregiver in such a way that they will feel welcome. People do not like to feel shunted around by the health care system.

The role of information

Information should be provided from the beginning. Information is empowering. It should be communicated in a way that invites questions and which enables the health care worker to check whether or not the information has been understood. Information ought to be pitched at the appropriate level for both child and caregiver. Paediatric

HIV and AIDS care and treatment involves a lot of medical facts and information about transmission, testing procedures, disease progression, ART treatment, side effects, opportunistic infections and nutritional advice. Health care workers need to be up to date. They have to be able to communicate information in simple, accessible language in order to help their patients understand their condition properly. This will help the child and his/her caregiver become active partners in the day-to-day management of their illnesses. While it is important to impart medical information and the primary point of contact with the child and caregiver is a medical one, it is essential to always be aware of the psychosocial needs and experiences of people who are infected with HIV.

Phases of psychosocial vulnerability

It is critical to understand the different phases of psychosocial vulnerability that the caregiver and the child undergo. Psychological stresses are heightened at the time of initial diagnosis as well as during episodes of illness. A terminal diagnosis produces especially acute distress. The family's response to the news that a child is infected with HIV and



AIDS will include shock, fear, guilt, disbelief, anger and sadness. It is not unusual for parents to request repetition of diagnostic tests in the hope that the outcome might be reversed. The acceptance of a child's HIV-positive status will be followed by grief as the family mourns the loss of their hopes and dreams for the future of the child. Some family members may become

so depressed that professional intervention will be required (ANECCA 2003: p203). Caregivers will struggle with feelings of helplessness, sadness and anger when the child has episodes of illness. It is during these periods that the implications of the disease become an emotional reality.

Addressing stigma

The stigma surrounding HIV and AIDS produces feelings of shame, guilt and self blame. These feelings will be especially raw at the time of first diagnosis for caregivers and for older children who understand the implications of their illness. It is probable that they themselves will arrive at the first consultation carrying some of the prejudices that surround people who are HIV and AIDS positive. Right from the beginning, then, health care workers need to be sensitive to the feelings that social stigma produces in individuals and address them accordingly.

People living with HIV and AIDS internalise – this means that they judge themselves according to the prejudices of their society. It is only when they have found a way to address this stigma that they can start living positively and looking after themselves.

There are ways that health care workers can assist in normalising HIV for the child and the caregiver by explaining that there have always been sexually transmitted diseases. The fact the most children are perinatally infected means that most of their mothers themselves were not well informed or feared undergoing an HIV test. The health care worker needs to be sensitive and not show any judgement of the mother. Instead they need to emphasise the constructive role that caregivers can play now that they have the necessary information.

Normalising HIV

HIV and AIDS is often believed to be a death sentence. Although everyone knows about the presence of HIV and AIDS in society, its reputation as a killer disease has resulted in a lot of ignorance about it. Health care workers need, therefore, to counter the fear of the illness right from the start by emphasising that HIV is treatable even though it is not curable. Discussing the biological facts of HIV with the caregivers and with children who are old enough to understand will also assist in addressing the myths about HIV. It will help explain its causes and make sense of the ways in which it needs to be treated. Many different beliefs surround HIV and AIDS. It might be associated with sin or witchcraft. It might be understood as a consequence of ignoring God's will or of disobeying the ancestors. Health care workers need to discuss these beliefs respectfully. They also need to dispel them with clear arguments that do not belittle people's beliefs. Health care workers will have to have examined their own values and beliefs so that they do not impose them on children and/or caregivers.

Most people associate HIV and AIDS with death. Health care workers can counter some of the pessimism that surrounds the condition by talking about patients (without mentioning names) who have made good progress. They can also offer hope and optimism by emphasising the benefits of treatment.



They can point out that there is a lot that people can do for themselves. Eating healthily, resting and seeking support are all good practices that caregivers and children can follow. The advice must be realistic, though. False reassurances are not really helpful. In the case of young children, the emphasis will be on educating the caregiver so that she can impart appropriate information to the child. Where children are old enough, such as adolescents, it is important for the health care worker to talk to them directly about medical concepts, stigma and all the other issues that are connected with their illness.

Ways of reducing stress for children throughout their treatment experience

Medical procedures can be painful and frightening. There are ways, though, to make them more acceptable and bearable. It can be difficult to adequately explain or prepare children for procedures that may be painful or frightening. It is particularly important, therefore, to prepare the caregiver for the medical intervention. They need to know that their reactions and attitudes will influence the child's response. Their support and presence can be of great comfort to the child during a medical procedure. They might, for example, hold a young child while the child is being given an injection or be able to entertain and distract the child. They might reward the child for his/her participation and cooperation. Health care workers need to stress the benefits of certain medical procedures to older children.

A simple but effective way of helping children feel comfortable in a medical setting is demonstrated by the The Teddy Bear Hospitals concept.⁵ Children are encouraged to bring their teddy bears to the medical centre. They then take the teddies through the same procedures that they will undergo themselves. This helps the children understand and accept their treatment. Any toy or doll could be used for the purpose.

⁵ The Teddy Bear concept was initiated in Norway. It is used in a number of hospitals in the United Kingdom. For more information see info@teddybear-hospital.co.uk.



Supporting caregivers

It is common for caregivers to feel helpless and overwhelmed. It is useful for them to know that there are a lot of concrete things that can be done with their children. These include:

- showing their children that they love them
- helping them feel safe
- keeping the home extra clean and teaching the children about being clean
- giving their children healthy food
- ensuring that their children get enough rest
- taking them for regular check ups
- getting early treatment
- encouraging them to go to school, make friends and play happily
- encouraging them to help others at home (Ramsden & Vawda 2007: p8–9).

2. Voluntary Counselling and Testing

Key Points

- Mother to Child Transmission accounts for over 95% of all paediatric HIV infections (ANECCA 2006)
- Health care workers can play an important role in encouraging pregnant mothers to receive PMTCT (Prevention of mother-to-child transmission) as well as in the early identification of HIV and AIDS-related symptoms in children.
- Health care workers need to know the national guidelines with regards to the age of consent for Voluntary Counselling and Testing (VCT).
- The health care worker will need to counsel both the child and the caregiver.
- Going for an HIV test can be a frightening experience for most people.
- Pre and post test counselling is essential and offers a vital point of contact.
- Always emphasise positive lifestyle and treatment options.

Understanding paediatric HIV and AIDS and the role of VCT in prevention and treatment

Most cases of paediatric HIV and AIDS result from MTCT. This means that more attention and effort ought to be made to encourage pregnant mothers to go for testing. It is vital that women collect their results. VCT is often the first point of

contact that a health care worker has with a caregiver and child. It is important to make sure that enough time is given to this process as it can determine whether or not caregivers will continue to use the support offered by the health care worker.

Voluntary Counselling and Testing

VCT involves much more than testing blood and offering a few counselling sessions (Boswell & Baggaley 2002: p1). It is the point of entry to other HIV and AIDS services. These include: PMTCT, the management of HIV-related illnesses, Tuberculosis (TB) control, psychosocial and legal support and further prevention, especially for young people who may be sexually active.

With regard to testing babies and children, the early identification of HIV makes it possible to:

- develop an action plan for regular follow-up and ART if required
- commence interventions to prevent common childhood infections
- access social development grants and other support structures.

The health care worker can play a critical role in helping prevent transmission and identifying early symptoms of HIV in children. In order to do this, the health care worker needs to be up to date with the relevant information about testing.

She needs to know about the different testing procedures and when and how to administer particular tests. Both the tests and type of counselling that accompanied them should be age appropriate. VCT needs to be provider initiated which means that members of the Health Care Team need to raise the need for testing at every given opportunity. In addition, it is also a good idea when working with the caregivers of infected children to enquire about the testing of other children in the family.

The value of counselling

One of the most important aspects of counselling is to ensure that the caregiver understands the benefits of knowing a child's status. This will increase the chances of the child receiving early treatment and care. Children need to start treatment as soon as possible as HIV tends to progress in children more rapidly than in adults, usually because they have a higher viral load.

There are some broad guidelines with which health care workers who offer VCT need to be familiar. These are:

- Knowledge of the National Guidelines and the age of consent⁶ for VCT and treatment in the country in which they are working. In South Africa, children under the age of 12 years need to seek adult consent before having an HIV test.

- Consideration of whom you are talking to. The health care worker needs, for example, to approach a mother differently from a father or a grandmother. She also needs to take the educational background of the caregiver into account.
- Establish a rapport with the caregiver. Encourage him/her to share his/her story by asking questions such as: "what brought you here today?" or "who referred you?"
- Find out how much they know about HIV and AIDS. Add to this information where it is lacking or incorrect. It is important to find out the fears they have about HIV and AIDS since these fears usually form the main obstacle to disclosure.
- Find out about their belief systems and work out how these affect their views about HIV and AIDS and treatment. Gauge how these views are influenced by religious, cultural and popular beliefs? This is important since it is related to how much education and motivation will have to be done if the child tests positive and needs medical treatment.
- Normalise the illness. Address fears, stigma and myths about HIV and AIDS.
- Joint discussion and assessment of the need to tell the child about his/her status, should he/she test positive. This will be influenced by the child's age and emotional maturity.

- Recognise and support the caregiver's role. Acknowledge the courage and strength that is needed for going through VCT process with the child. (Adapted from Adherence Networking Group 2006: pp96–101.)

The purpose of VCT

VCT aims to help the child and his/her caregivers cope with the emotional and medical challenges they experience as a result of HIV infection in the family. Counselling can help HIV-positive children adopt a positive attitude. This, in turn, helps them prolong and improve the quality of their lives. It will also make it more likely that they will adhere to their treatment regimen (ANECCA 2006: p208). The counselling process begins with the first contact with the child. This may be in a clinic when a child is brought in sick, at home during a home visit or at school. It is common for a child to be accompanied by a parent or other family member when they first arrive at a clinic. As a general rule, interactions with the child should take place in the presence of a parent and, when appropriate, with other family members or siblings, until the health care worker has gained the confidence and trust of both the child and the caregiver. Having more than one family member present enables the counsellor to observe the reactions and interactions of both child and family. It also strengthens the child's support network. In most cases, though, one caregiver

⁶ According to the Centre for Child Law (Children's Act 2005 : p30–33), legislation in South Africa allows a child to give consent for HIV testing from 12 years onwards. However, the child must have the capacity to give consent. The assessment of this capacity can be undertaken by the health care worker as things stand at the moment although there is a move to consider regulations governing who has the power to assess a particular child's capacity for making an informed decision of this kind.

(often the mother) will accompany the child. Children over the age of 12 have the right to be counselled on their own. Adolescents can be counselled alone or with a family member present. The choice should be theirs.

VCT can be divided into two categories: for children under the age of 12 (who require the consent of a parent/caregiver before they can be tested) and pre-adolescents who are 12 years old or older. Many of the principles of VCT are the same for both categories. The main difference is that the primary client is the caregiver in the case of children who are under 12, while adolescents over 12 are themselves the primary client.

For children under the age of 12 years

In many ways, the health care worker's primary client in the case of children under 12 is the child's caregiver. It is the caregiver who ultimately decides how much to involve and tell the child. Until the child is told about his/her status the health care worker will see the caregiver alone. Another family member will have to look after the child during these counselling sessions. It helps to have a waiting room in which children can occupy themselves with toys or books.

Testing symptomatic children in order to provide appropriate care can be done at any age. It is necessary, though, for health care workers to seek consent for testing from the children's parents or caregivers. The issue of consent is very important when testing a child under the age of 12 for HIV. A parent/



legal guardian must sign a consent form. If a parent/guardian is not available, a number of other people can sign the consent form: the superintendent of a hospital, a police officer, the court, a child commissioner or a statutory social worker.

The parent/legal guardian of the child should be consulted in order to assess the emotional maturity of the child and determine how much information they are ready for. The results of an HIV test should not be disclosed to a child who is not old enough to understand them.

VCT for babies

Babies will be tested to see if MTC transmission has occurred. The test used is called the PCR test. It is best done when the baby is 6 weeks old or as soon as possible thereafter. This will facilitate early medical and psychosocial intervention

in the case of a positive result. Mothers who took drugs to prevent the transmission may find it especially difficult to accept that their child has tested positive. Other mothers may have slipped through the PMTCT net or tested negative themselves. Some mothers only get their children tested when signs of an AIDS-defining illness become evident. Some mothers refuse to accept their child's diagnosis. Many mothers will also deny their own HIV-positive status, especially if they are in good health. Health care workers have, therefore, to find direct but sensitive ways of relating to mothers (and other caregivers) so that they do not delay getting antiretroviral treatment for their children. It is also important to encourage mothers who know their status to have their CD4 counts done so that they can be put on treatment if necessary. Consistent adherence to treatment is also vital. Ongoing and long-term support will be required to help the caregiver and child persevere with the treatment and face the challenges presented by the illness.

VCT for children over 12 years

Children over 12 will themselves be the health care worker's primary client. The adolescent might, however, arrive for the first consultation with a caregiver. The health care worker needs to discuss the legal position with the caregiver and child. The child should be given the option of individual counselling. The importance of the caregiver's support should also be stressed though. The health care worker needs to assess the child's emotional maturity and capacity in order to gauge

whether they would gain more from individual sessions or would be better off receiving counselling with a caregiver. Pre and post test counselling for teenagers is similar to that done with adults. The language, though, should be adapted to their level. The health care worker should make especially sure that the adolescent has understood everything that has been said. Reproductive health issues will also need to be discussed with adolescents. It is common for caregivers and/or adolescents not to collect their results. In such situations, health care workers will need to follow up the case.

3. Disclosure

Key Points

- Disclosure is a process that takes place over time. It is not a once-off event.
- Most caregivers find it difficult to disclose the child's status to the child. They will need guidance and support to do so.
- Disclosure needs to take into account the fears, wishes and views of caregivers. They should feel that they are in control of the process.
- There is no blueprint for how and when to disclose to a child. There are, however, some useful guidelines.
- Children often react badly at first to disclosure, but with support come to terms with their diagnosis.
- The caregiver is the person who is best suited to disclose, but in exceptional circumstances a health care worker may



need to undertake the disclosure. This might involve telling the child about his/her HIV status, or specific family members such as siblings or even other people such as friends.

Understanding disclosure and its importance in the role of effective treatment

Disclosure refers to the process of telling a child about his/her HIV status. Although disclosure might seem to be a once-off event, it is actually part of an ongoing conversation with a child about his health. The main reason for telling a child about his HIV status is to help him understand the illness so that he can play an active role in his health as well as know how to face the challenges that come with living with an illness (Children's Right Centre 2007a: p11). Ideally, disclosure should widen the network of support that is available to both the child and the caregiver.

Despite the benefits of disclosure, it is common for caregivers not to disclose the child's HIV status to either the child or close family members. This is due almost entirely to the stigma, taboos and myths that surround HIV and AIDS. It takes a lot of courage to tell someone that they are HIV positive when a society is in denial about the illness. The situation is even more complicated when a mother who is HIV positive herself has to tell her child that the child is also HIV positive. The whole situation requires great sensitivity and care on the part of the health care worker.

The role of the health care worker

Health care workers play an important role in helping caregivers find the courage and confidence to disclose. Health care workers need to guard against judging the caregiver negatively. It is important to focus instead on building a relationship of trust with the caregiver. It is this relationship which will enable the caregiver to understand his/her fears about disclosure. The caregiver will not be able to disclose to the child until he/she has worked through these fears. The relationship between the health care worker and caregiver has to be based on confidentiality. The health care worker's ability to answer questions with appropriate and relevant information and their skill in communicating the benefits of disclosure will be critical. The health care worker also needs to make certain that the caregiver can be assured of receiving ongoing support, whatever their circumstances.

It will probably be necessary to spend several sessions counselling the caregiver about the need to disclose. The health care worker might find it helpful to encourage the caregiver to join a support group where other people can testify about the positive outcome of disclosure. The medical treatment of the child should continue even without disclosure. The child must know about his/her illness in the long term, though, if he/she is to face the challenge of living with HIV and AIDS effectively. While disclosure does not solve all the problems related to living with HIV and AIDS,

it does place the child and the caregiver in a stronger position to respond to these problems.

What are the benefits of disclosure?

The benefits of disclosure include:

Benefits for the child:

- Empowers the child to make choices
- Communicates respect for the child and builds trust between the caregiver and the child
- Invites the child's active involvement in his/her own health. This is an important component of successful treatment
- Explains the need for medication, promotes cooperation and encourages adherence to treatment.
- Increased cooperation leads to better health. Children who understand something about healthy living and HIV will be more likely to cooperate with adults when it comes to taking medicines, having blood tests and taking good care of themselves
- Positive living strategies that help the child live with HIV become more possible
- Lack of information or incorrect information can interfere with adherence
- Understanding HIV and AIDS equips children with the knowledge and confidence they will need in order to counter the stigma and rejection that attend the illness
- Helps adolescents make informed choices about sexuality

- Children can tell from a very young age when something is not right in the home or with their health. If they are not told what the problem is, they will imagine that it is worse than it really is.

Benefits for the caregiver:

- Relieves the stress and anxiety that accompanies secrecy and deception
- Being open and direct with one's child makes it easier to find ways to normalise the situation
- Sharing positive messages with their child will lead to the caregiver feeling less helpless and hopeless. It will also instil optimism in the child
- It becomes much easier to access medical services, care and support when this can be done openly
- Helps protect an HIV-positive caregiver from reinfection and from infecting other people
- Establishes the conditions in which safe sex can be negotiated
- People who disclose help reduce stigma and discrimination about HIV and AIDS in the community
- Enables the family to plan for the future.

It is also necessary to state the very real and tangible consequences of disclosing. These are different for the child and the caregiver. They will need to be explored in depth as they are often the reasons why a caregiver does not disclose to a child.

Disadvantages for the caregiver

- Could negatively affect relationships with sexual partners, family, friends and people at work
- Might lead to abandonment, rejection, blame and isolation, especially if a partner leaves the caregiver.

Factors that prevent caregivers disclosing

- The caregiver's denial about his/her own HIV-positive status.
- The caregiver's fear of confronting his/her own feelings of guilt and helplessness.
- The caregiver's fear of the child's anger if the child's illness is a result of MTCT.
- The caregiver's fear of the child's reaction: self harm, suicidal thoughts, telling others, for example.
- The caregiver's inability to face the reality and desire to get rid of the problem. In some cases this can even lead them to abandon the child or place him/her in an institution.
- The caregiver's fear of their spouse's reaction. These would include blame, rejection and domestic violence.
- The caregiver's fear of rejection by friends and family members.

Beliefs and attitudes about what is best for children

It is helpful for the health care worker to know how to counter these fears in a sensitive and participatory way. It



is best to help the caregiver come to the realisation of the benefits of disclosure herself rather than preaching to her. This will require time and patience. Many of these beliefs are seen by caregivers as good reasons not to tell the child about his/her status:

- **Children are too young to know about HIV and AIDS.**
 - Most research shows that this is not the case. Children learn to cope very quickly if they are given consistent, accurate and age-appropriate information.
- **Childhood is a time to be happy and there is no need to burden children with sadness and worries.**
 - Children cannot always be shielded from reality. Instead of feeling happy and carefree, they will feel betrayed and alone once they discover that

information about their health was withheld from them at a time when they were mature enough to process it. Children know more than we think they do. Attempts to protect them from reality can backfire and provoke anxiety.

- **Caregivers know what is best for the child.**
 - Children have a right to participate in their own health care, in accordance with their level of development.
- **Children will feel bad and depressed.**
 - Children gain strength and resilience from being trusted and given some responsibility for their own health and welfare.
- **Not telling children protects them from stigma and despair.**
 - Sooner or later they will find out, perhaps by accident or from a third party. Their trust in the caregiver will then be diminished.
- **Just thinking about telling my child makes me feel exhausted. I just don't have the energy to think about it?**
 - Making sure that the child doesn't find out by accident also takes up a lot of energy. Keeping a secret is very draining.

- **Children do not need to know about bad things like illness and death.**
 - Children are able to sense when things are not right. If adults do not take them into their confidence they will think things are so bad that no-one can talk about them.
- **Telling means having to tell the whole story. Neither of us are ready for it.**
 - Disclosure is a gradual process. The child can be given only the amount and kind of information that they are capable of absorbing.
- **She doesn't know anything yet.**
 - In most cases, children often know a lot more than caregivers think. There is a lot of talk about HIV in the media, at school and the general society. Children also pick up information when they attend clinics
- **It is best to avoid talking about medicine and illness to a sick child.**
 - Children feel more anxious when they do not know what is making them sick. Ignorance also encourages non-adherence.
- **A child who asks questions can be told that their medication is for something other than HIV.**
 - Giving wrong information can cause problems later

and lead to a breakdown of trust between the child and the caregiver.

- **Telling about HIV means having to tell the child about his/her parents too.**
 - Children do not have to be told everything at once. Children feel safe and secure when parents have clear boundaries.
- **Children can't keep secrets. The whole family will be exposed to rejection and stigma.**
 - Most children can understand the need to keep certain things within the family.
- **Telling him could affect his cooperation in taking ARVs.**
 - On the contrary, learning about his status will motivate the child to take his medication.
- **The child will have to deal with stigma.**
 - Children can learn how to deal with rejection by teaching them the values of respect and tolerance.
- **I'll tell her when she is older.**
 - Many children feel angered and betrayed about having information withheld from them for years.
- **She's still suffering after the death of his/her parent. Its not right to tell her now.**

- This might be appropriate in the short term. The child, though, will continue to want to know the cause of his parent's death.
- **HIV is associated with sex. In many cultures it is taboo to talk about issues related to sex with children.**
 - Accepting sexuality is part of a value system that emphasises respect and concern for oneself and others.
- **Fear of accepting or inviting death.**
 - Knowledge can lead to informed decisions and opportunities to receive the kind of medical care and support that will prolong life. (Adapted from Adherence Networking Group 2006: pp103–104.)

Whether these fears are rational and others are irrational, they result, understandably, in caregivers feeling reluctant to disclose to their children. In order to overcome these fears, health care workers will have to exercise great patience, sensitivity and empathy.

The process of disclosure

Disclosure should be seen as a process of telling a child that he/she has HIV and AIDS and explaining to the child what this means. It is a two-way conversation that involves:

- speaking with the child over time about his/her illness
- disclosing the specific diagnosis at an appropriate time.

This can be gauged by the type of questions the child asks or the comments he makes. Sometimes the right moment will occur naturally with a new step in the treatment process

- continuing the dialogue with the child after the initial disclosure in order to help the child understand and cope with her new knowledge.

In the course of the process of disclosure, the child should learn about the actual diagnosis, the stages and nature of the disease, possible health changes, strategies for healthy living (including adherence to ART), risk factors, responsibilities and how to cope with possible negative reactions and stigma.

It is important for a caregiver to be aware that there are ways of disclosing to a child that might be damaging and inappropriate. The experience of living with a disease such as HIV and AIDS is not easy for medical and social reasons. Caregivers need to know that the child has to be strengthened in order to cope with this reality. The child should not be left feeling hurt, confused, angry or scared. The following are inappropriate ways in which the child might learn about his illness:

- accidentally (e.g. child overhears people talking or reads something left lying about)
- carelessly (without really thinking about how to disclose)
- in anger (e.g. in reaction to something the child has done or said)

- an unplanned response to a child confronting adult caregiver or health care worker
- after the child has already worked things out for him/herself
- when a child is dying (Adherence Networking Group. 2006: p105)

Disclosure is something that has to be well planned. Many caregivers go through different stages in the process of preparing themselves to disclose to the child. It is useful for the health care worker to alert them to these stages.

Different phases of preparing to disclose

(Adherence Networking Group 2006: pp80–84)

The phases are:

The secret phase: This phase follows immediately after hearing about the child's diagnosis. Most caregivers will want to keep this information to themselves or only tell a partner, close friend or family member. The only other people who will know the child's status at this time will be the health care worker involved in the care of either the child or the caregiver herself. At this stage, the thought of disclosure causes anxiety and denial.

The exploratory phase: In this phase, the caregivers may confide in a person who is especially close to them and test their reaction. Other people's questions (e.g. about clinic

visits) are met with vague replies or false explanations (e.g. that the child has another illness). Caregivers will give their children incorrect but plausible explanations for clinic visits. They will begin, though, to accept and acknowledge the need for disclosure at some vague or distant time in the future.

The preparatory phase: Caregivers may now be prepared to disclose to a wider group of people and be interested in hearing about the experience of other caregivers and children. They begin to think more concretely about ways to disclose to the child although they have not yet made a definite decision to do so.

Disclosure phase: Caregivers take steps to disclose to their child. If confronted by the child, they try their best to give clear answers. It is advisable that a lot of preparation takes place in this phase. The health care worker can help the caregiver identify the approach that is best suited to a particular child, based on the child's age, developmental stage and level of maturity. There is no blueprint for disclosure but there are some important general principles.

Guidelines for disclosure for all ages

- Always keep in mind the personality and situation of a particular child, caregiver and family.
- Create a climate where the child will feel free to ask questions. Try not to avoid the questions that the child may ask. If you don't know the answer to a question,

undertake to find it out.

- Anticipate and plan how to respond to possible responses (verbal and non-verbal) of the child.
- Anticipate and plan for the impact on family members, friends, school and community members.
- Be led by the child (their questions, reactions) about the amount of information to give at a particular time.
- Use language that is appropriate to the child's developmental level, level of education and emotional readiness.
- Keep what is said simple, clear and honest.
- Remember that children often believe that illness is their fault. They might have to be reassured that are not ill because they have done something wrong.
- The post-disclosure period is critical. Monitor the child's behaviour (sleeping, eating, emotional reactions, school performance). You might need to refer the child to a social worker or health care worker if there are any negative changes

Specific guidelines for different age groups (adapted from Adherence Networking Group 2006: pp82–84)

Giving information to preschool children under the age of 6

- Emphasis should be on the child's health and illness.
- Disclosure of HIV status will generally be delayed till later.

- Give information in response to the child's questions ("why does the doctor take my blood?") or reactions (e.g. refusing to co-operate with procedures).
- Give explanations that answer questions – don't add unnecessary detail.
- Use play activities (e.g. doctor-doctor or dolls) to allow the child to communicate any concerns or express feelings indirectly.
- Younger children can be told about germs in general. They can be told the name of the specific germ itself when they get older.
- Young children need reassurance and comfort. They need to know that doctors and medicine can help them feel better.

Giving information to primary school children

- Give more detailed information with concrete examples.
- If a child asks for more information (e.g. "What's the germ called?" or "How did the germ get in my body?"), give short, clear answers.
- Stop when the child seems satisfied. S/he can always ask for more information later when s/he's ready.
- Help the child deal with possible stigma.
- Reassure the child that s/he can ask further questions or express more concerns.
- Focus on general health and hygiene (eat well, keep clean, look after teeth, rest).

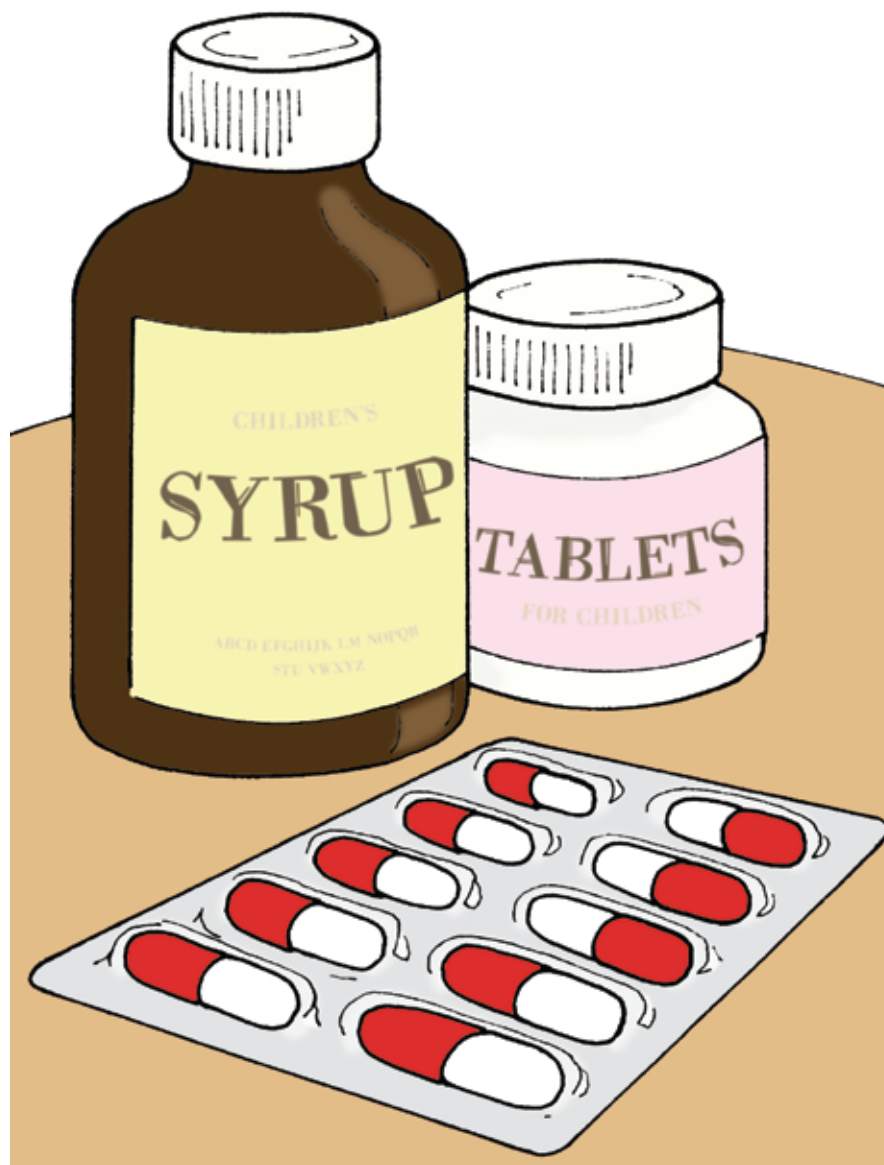
Giving information to adolescents

- Accurate and more detailed information can be given in response to questions or to augment information given earlier.
- Realistic information about health status should be given.
- Ways to live meaningfully with HIV is often of more concern to adolescents than the actual mode of transmission.
- Assuring them that their status and what they say is confidential is very important.
- Normal teenage striving for independence may complicate the response to disclosure (e.g. result in a decline in adherence).
- Issues of possible disclosure to others should be discussed. The adolescent should make his/her own decisions on this matter.
- Assurance of support and willingness to help should be given without seeming intrusive. (Adherence Networking Group 2006: pp82–84)

4. ART Adherence

Key Points

- There are demands and challenges involved in giving children antiretroviral treatment (ART).
- There is a need to link ART to child development in order to ensure successful treatment.



- The key elements of successful adherence are good relationships between the health care worker and the caregiver and the caregiver and child as well as disclosure of the child's HIV status by the caregiver.
- It is important to give the caregiver the relevant medical information linked to ART.
- Adherence counselling is vital for promoting adherence.
- There are different ways of monitoring adherence.

Introduction to ART

ART refers to antiretroviral (ARV) treatment. ARVs do not cure AIDS but work to reduce the virus from replicating itself. Not all children with HIV will need to take ARVs. Children will need to be clinically assessed in order to determine whether or not they are ready to start treatment. If a child stops taking the drugs, the virus spreads again and the virus might then become resistant to the ARVs. Different ARVs are used in different countries. The health care worker will need to familiarise herself with the drugs that are being used locally. The drugs that are used in state hospitals and clinics are often different from those that are used in private medical care.

The child's health status is not the only factor that will determine whether or not a child should be on ART. The level of support in the home is another vital consideration. The caregiver is the key person. Children (especially those under 12) are dependant on their caregivers. The health care worker will need to discuss the best interests of the child with the

caregiver and motivate her about the importance of her role. The child's very existence might depend on drugs being taken correctly and regularly each day.

Knowing the medical facts and assessing adherence

A medical and social assessment should take place before ART begins. Most children (and this includes adolescents) need a caregiver to supervise the taking of medicines. It is also important to have a responsible back-up person to replace the caregiver should he/she get sick or need to be elsewhere. The assessment process includes a range of procedures and processes. It begins with an HIV/AIDS test. This is followed by diagnosis and an assessment of the progression of the disease in the child. A decision must then be taken about the treatment to use and when to start it. The dosage must be worked out, feeding and nutrition information provided and support and follow up for the child and caregiver planned.

The caregiver will need to be taught about:

- the names of the drugs
- how often and in what quantities they should be taken. This is referred to as the medicine schedule (Adherence Networking Group 2006: p109)
- possible toxic reactions to the ART
- dealing with side effects
- identifying medical/clinical signs which need urgent attention

Health care workers might be concerned that talking about side effects will frighten the caregivers and the children. This could make them refuse ART. However, failing to inform the caregivers / children can compromise trust and credibility in the health care worker as well as in ART. In some cases, it could even put the child's life at risk. Adherence is improved when caregivers/children know what to expect. Practical experience shows that it is better to share this information with caregivers in order to equip them with basic understanding. This will help them know what to do and how to assist their child.

ART adherence will specifically focus on the need to ensure that the child takes medication according to treatment plan and schedule. It is necessary to check carefully that the caregiver understands all the information that is given at each stage of medical support and counselling.

Circles of support

It is important to broaden the support network of the child and caregiver. This will strengthen their motivation and help support them on the long road of treatment. Some possible options are:

- Caregiver–caregiver support: Many caregivers are willing to share their experiences with others, especially those just starting on ART. Caregivers new to ART may find it easier to share uncertainties and anxieties with another



caregiver rather than with a health care worker.

- A buddy system can provide emotional support. A buddy is a friend, family member or someone else affected by HIV and AIDS (e.g. another caregiver) who agrees to offer support to the caregiver.
- A child may receive support from another child. This child may or may not be HIV infected herself. She may only know that the child has a chronic illness. Peer support is particularly valuable for adolescents, especially if the young people involved are able to draw on similar experiences.
- Directly observed therapy (DOT). This involves individuals taking one or more of their daily doses under the supervision of another person. This person will usually have been trained for the task. This may be essential for children living in difficult circumstances, e.g. in foster care or in institutions.
- Support groups can provide both caregivers and children with the emotional and practical support of others who face similar challenges.
- Community projects. Involvement in community projects may offer opportunities for informal support as well as tangible benefits such as income generation. (Adherence Networking Group 2006: p51)

Understanding adherence

Adherence refers to the degree to which the caregiver and the child follow a treatment plan (Adherence Networking Group 2006: p11). It includes the practical details for taking

the required medication: recommended doses, time and method. It is essential that the child and the caregiver understand that the success of ART depends on high levels of adherence. Adherence is necessary to maintain control over the viral load, build the immune system and prevent the development of viral resistance. The adherence plan has to be tailored to fit the circumstances of the child and caregiver in order to ensure that the child does not miss more than 3 doses per month. Non-adherence can take the form of missing a dose, delaying a dose or taking anything less than 100% of the medication. It can be expected that at some stage the child will fail to adhere strictly to the ART schedule. For this reason it is essential that the health care worker maintains ongoing contact with the child and caregiver. Regular review and re-motivation sessions will be necessary. Identify and solve the problems that prevent adherence as soon as possible. The health care worker will learn about adherence problems in different ways. These might include self reporting, late prescription repeats, pill counts, bottle checking or checking diaries and calendars. Each of these methods has limitations when used on its own. The viral load can also be a good indicator. You cannot automatically assume a connection with non-adherence, though, as an increase in the viral load might also be related to other factors such as viral or bacterial infections (Adherence Networking Group 2006: p55).

Non-adherence

Some of the reasons underlying non-adherence might be related to:

- forgetting: this is very common
- information confusion, misinformation, misperceptions, competing and conflicting messages from family and friends, as well as religious or cultural affiliations
- Medication-related issues: sharing doses, running out of medication due to a missed visit or an extended holiday, forgetting, finding pills too difficult to take (too many, too big, too complicated a schedule)
- medical effects of medication: side effects, changes in health, opportunistic infections
- caregiver concerns and problems: lack of finances, shortage of food, depression, substance abuse, neglect
- effects of non disclosure – secrecy involves not being able to take medication in front of others
- change in the routine of the child and caregiver.

It is important to anticipate these sorts of complications and address them in the adherence counselling sessions. The health care worker needs to create systems which will make adherence easier for the child and caregiver. It also helps to reinforce the message of the importance of adherence at every opportunity. All health care team members should reiterate this message whenever possible.

Systems of support can take various forms. These include

pill boxes, alarms, medical fact sheets, a tracking system and systems of recoding information to pass onto colleagues. The information should include specific information about adherence and changes in the health status of the child (Adherence Networking Group 2006: p56). Effective adherence counselling will address the practicalities of working out a treatment plan/schedule and the administration of medication. It is important to identify which factors facilitate and hinder these areas of treatment.

General principles for adherence counselling

There are a number of different variables that need to be in place in order to ensure that the child and caregiver are prepared to start ART.

Communication with child and caregiver

- Take time to develop empathetic, caring and respectful relationships with the child and the caregiver.
- Work with belief systems that affect attitudes to ART and medical care. These include beliefs that view illness as punishment or ideas that religious faith will cure the illness on its own. It is not advisable not to challenge beliefs directly, though, as this can undermine trust and confidence.
- Acknowledge the severe implications of HIV and AIDS for the family.
- Extend the system of support where possible.

- Listen attentively to the presentation of problems. Problem solve together.
- Use terminology that is accessible.
- Use culturally appropriate language and metaphors.
- Allow time for questions.
- Check understanding by letting caregiver or child teach you or have them draw diagrams etc.
- Assess the level of motivation.
- Check to see if home circumstances can support ART.
- Encourage disclosure without putting pressure on the caregiver. Rather weigh up the effects of disclosure and non disclosure.

Health care team

- Adopt a common approach to education and avoid conflicting messages.
- Constantly check and reinforce understanding of the regimen.
- Keep good records.

Pre-drug counselling

- Explain why high levels of adherence are essential. Discuss the consequences of poor adherence. Non adherence limits the treatment options.
- Assess the age of the child and the appropriateness of administration of medication e.g. is the child old enough to swallow pills?
- Careful preparation can save time and avoid problems.

- Develop a treatment plan (link this both to the practical details of how, when and how the medication will be taken as well as a psychosocial support plan).
- Have a practice run for at least a week using mock medication. Review the process and find workable solutions for problems.

Monitoring adherence

- At every visit ask about the taking of medication.
- Use concrete questions with specific time references (in the last week, since the last visit) to get good information.
- You are more likely to get reliable information if you ask questions in a non-judgemental way. “How many doses were missed?” is less accusatory than “Did you miss any doses?” Ask which medication was the hardest to take and why this was so.
- Seek solutions rather than dispense blame.
- Give realistic reassurances.
- Be consistent and flexible.
- Review the treatment plan constantly.
- Adjust adherence plan to suit the child and caregiver. Use three-stage model of adherence counselling at different stages.
- Acknowledge success of treatment. Recognise and reinforce good adherence.
- Simplify if possible by minimising pill burden/dose frequency /dietary restrictions.
- Tailor the approach to the age/developmental level/

emotional state of the child.

- Help the child understand the illness and disclosure is particularly relevant.
- Explore school performance, leisure interests, friendships.

How can we support caregivers in helping children adhere to their medication?

There are specific demands for taking medication at different stages of a child's development. These factors have to be taken into account when administering medication.

Babies

Babies are totally dependent on caregivers. They cannot understand the need for medication. An anxious first-time mother might find it especially difficult and painful to give medicine to her baby. These difficulties increase if the baby is premature and sickly. Premature babies need to be fed more often and may have feeding difficulties that might, for instance, be related to thrush. This could lead to a reduced intake of medication. Risk factors such as dehydration are also more common.

Medication factors

Babies usually need special syrups and solutions. These have to be accurately measured with a syringe or dropper. An elderly caregiver might have difficulty with this process and with reading the correct measurements. Not all drugs for babies

come in liquid form, though – some drugs can be crushed, dissolved in water or sprinkled on food. As babies grow, their medication will need to be adjusted. This might create confusion about the correct doses. Babies sometimes resist strong or strangely textured medication. Some medication might need to be refrigerated

Toddlers/Preschoolers

They are also dependent on the caregiver to administer medication. However, the child's increasing control over his/her body increases both his/her capacity for cooperation and non-cooperation. Children at this age still require frequent meals. This can make it difficult to coordinate meals with medication. It is also quite likely that a toddler will be looked after by different people at different times. All these people will need to be familiar with the child's medication schedule.

Children of school-going age

Children of school-going age are physically and mentally capable of both cooperation and resistance. Caregivers who struggle to direct a child's behaviour with regard to things like homework and tidying up, will find it difficult to enforce adherence to medication. A child who enjoys a good relationship with his caregiver is more likely to put up with the discomfort of taking medication. The child's understanding of his/her illness will also increase his/her motivation to cooperate with the caregiver and "help control the virus". If the child has been told very little about his illness, he will

probably be less likely to cooperate, especially as he grows older. Older children are strongly influenced by peer pressure. They may resist doing things that make them feel different. It is necessary, therefore, to teach the child that he/she is special rather than different.

Adolescents

Adolescents have the capacity to understand their illness. They know that HIV and AIDS is incurable at present. This kind of knowledge can lead to denial. It can also result in a strong orientation to the present. They may engage in high-risk behaviour, believing this will enable them to get the most out of life while they still can. Neither denial nor risky behaviour is consistent with adherence. Other possible reasons for non-adherence by adolescents might relate to their need to feel independent and invincible. Many adolescents distrust and resist authority figures. They are susceptible to many influences. Adolescents living on the streets will usually have chaotic lifestyles without access to regular food and family support. Adolescence, generally, is an emotionally charged time due to hormonal changes. These can be intensified by medication. It is important to invite adolescents to take responsibility for their health rather than order and instruct them. They respond to discussion and efforts to clarify their fears and concerns. Peer support is often the most appropriate and valuable source of support for this age group (Adherence Networking Group 2006).

General factors to consider about medication

- Make sure the caregiver knows if medication has to be refrigerated.
- Practice measurement and administration with caregivers using mock medication. Get caregivers to demonstrate how they would measure and administer medication. Repeat this activity on subsequent visits.
- Non-disclosure may limit when, where and who gives the child medication.
- Review and help solve difficulties.
- It is important to refer the child and caregiver to other health care workers when necessary. Feeding problems or persistent vomiting, for example, require specialised attention.
- Identify problems in administering medication. Ask specific questions. Explore options based on the age of child (injections or crushing and dissolving pills might be appropriate for babies, for example).
- Medication dosages will change with growth spurts.
- Tailor routines to fit the needs of older children. They can participate in managing their medication but still need adult supervision.
- Children of school-going age can swallow tablets. This allows some degree of flexibility as to when medication can be taken.
- Taste and texture may be an issue. There are strategies for overcoming these problems. The child might be given some chocolate powder, for example, or be allowed to suck on a piece of ice.

- Involve children as much where possible with regard to how to take their medication but not on whether to take it.
- Older kids can be encouraged to keep diaries and records. These can be shown to the health care worker at each visit.
- Show appreciation through appropriate incentives. For example, you might reward the child by doing something special with the child, such as reading her favourite book or baking together

The three-stage adherence model

A three-stage model has been designed in order to organise the entire treatment support process (Adherence Networking Group 2006: p67). The health care worker needs to go through each stage thoroughly with the caregiver and child (in the case of older children). The broad aims and focus of each stage will be outlined below while a more specific check-list will be included in the ART adherence cue card number 9. The stages do not have to be followed in a linear way. The health care worker will probably have to move between stages 2 and 3, depending on the needs of the situation. The steps in stage 1 should be followed quite closely, though, since this stage is related to the initial point of reference and assessment.

The three stages include:

Stage 1: Pre-ART assessment and preparation

- Assessment of the capacity and readiness of the caregiver/ child to start ART (includes medical, psychosocial assessment and readiness assessment).

- A decision to start ART. This is the caregiver's decision made with the support of the health care worker and, where possible, the involvement of the child.
- Preparation for integrating ART into the life of the child and caregiver – development of a treatment plan.

Stage 2: ART initiation and maintenance

The second stage involves the beginning of treatment. This entails an initial adjustment. The period of adjustment may involve unexpected difficulties and challenges for the caregiver or child. They will need support to meet these challenges. The crucial need for adherence must be constantly reinforced. All members of the health care team need to play a role at this stage. Different strategies to maintain adherence need to be explored and tried out by the child and the caregiver. The health care worker needs to work out ways to contact families who live far away or who have no access to a telephone. The use of home visits can be helpful for assessing and encouraging adherence. Since caregivers and children usually feel relaxed in their homes and more able to discuss difficulties, health care workers need to be aware of the possible side effects of specific kinds of medication. Efavirenz, for example, can have neuropsychological side effects such as anxiety, depression, poor attention at school and hyperactivity. Address problems as soon as they arise, for instance, there might be a need to simplify medication or to discuss ways of managing side effects.

Stage 3: Re-motivation and/or treatment change

This stage anticipates a number of different situations. These include a decrease in adherence, the experience of side effects or toxic reactions drug resistance and the failure of the treatment. A thorough assessment might indicate that there is a need for a change in the treatment plan. The caregiver and child need intensified support in any of these circumstances. They will need to receive extra guidance and encouragement. If non-adherence is identified as an obstacle, the health care worker will need to discuss and reiterate the original reasons for starting treatment (Stage 1). The long-term benefits need to be stressed. The difficulties and monotony of sticking to a treatment plan need to be explored. There may be a need for additional contact with the child and caregiver between clinic visits in order to help them remember the daily treatment times and administer the drugs properly. The caregiver and child will have to understand the different requirements of the new (and therefore, at least to start, more complicated) regimen when there is a change in treatment. This involves using elements of the pre-ART counselling stage.

Theory to Practice Card Number Five: Pre-Voluntary Counselling and Testing guidelines

1. Background

Before a health care worker tests a young child or infant for HIV, voluntary counselling has to be offered to the caregiver so that the caregiver has the opportunity to make an informed choice as to whether or not they want testing to proceed. In terms of South African law, children under the age of 12 cannot be tested without the consent of a caregiver. A child over the age of 12 will need to be consulted as to whether or not they agree to undergo a HIV test. They do not require parental consent to have a HIV test. The health care worker or counsellor will counsel the caregiver in the case of a child under 12 and the child/adolescent in the case of children over 12.

2. Objectives

- This card outlines some of the steps the health care workers needs to go through to prepare
- the caregiver of a child before VCT
- the adolescent

3. Key terms

3.1 Voluntary Counselling Testing: Voluntary counselling and testing (VCT) for HIV is the process whereby an individual, caregiver or couple undergo counselling to enable them to make an informed choice about being



tested for HIV. This decision must be left up to the individual/s concerned. They must be assured that the process will be confidential. (Boswell, D & Baggaley. R 2002: p1)

4. Key actions for health care worker

The health care worker needs to adapt the steps in this checklist to the needs of the particular client, either a caregiver or adolescent

4.1 Introduction and greeting

- Introduce yourself and establish a rapport and trust between yourself and the caregiver and/or adolescent.
- Explain your role, the purpose of VCT and the importance of confidentiality
- Confidentiality: – in the case of talking to a caregiver, you need to explain that you will not talk to their child without permission. The same principle applies to an adolescent. You will not talk to the adolescent's caregiver without the adolescent's permission.
- Emphasise that the result of the child's HIV test is confidential information. In certain situations, however, the results may have to be disclosed (for example, as evidence in court).
- The result may have to be shared with other members of the health care team. This would be the case if, for example, the client needed to be seen by another counsellor.
- Explain how much time will be needed for this session and briefly outline the content of the session.

4.2 Explaining the importance of consent

- **For children under the age of 12 years:**
- Children under the age of 12 cannot be tested without the consent of a caregiver.

- Explain the role of the caregiver in making decisions.
- If the caregiver does not want the child to be tested at this session, then encourage the caregiver to bring the child to the clinic as soon as the caregiver has made a decision to test the child.
- Emphasise that the most important factor in deciding to opt for VCT is the interests of the child.
- **For children over 12 years**
- Emphasise that the most important factor in deciding to opt for VCT is in the adolescent's interests.
- Conduct an assessment of the child's cognitive and emotional development. If you are concerned about the child's level of maturity (both chronological and emotional maturity, for example in cases of disabled children), encourage parental involvement. Children over the age of 12 are often not ready to deal with counselling and testing on their own. If they insist, though, proceed with the VCT process.
- It is the child's decision whether or not to involve a parent. While adult support is the ideal and should be encouraged, the wishes of the client (in this case, the adolescent) must be respected.
- If the adolescent is not ready to test, encourage him/her to return when he/she is ready.

4.3 Assessing the situation and the possible risk of HIV infection

- Help the caregiver/adolescent tell his/her story, clarify

any misconceptions, provide clear facts and allow time for questions

- Ask an adolescent about her background – age, experience, employment – as this will help you get to know her and her support network.
- Discuss the reason for bringing a child who is under 12 for testing with his/her caregiver (voluntary /referral).
- Determine the mode of transmission and how recent it was. You could ask questions such as, “Where do you think you might have contracted HIV?” This is necessary as it helps the caregiver/adolescent plan how to prevent reinfection and the infection of others.
- In the case of a vertical transmission (that is, from mother to child), time must be spent addressing the mother's concerns, possible self-blame and discussing the impact of HIV on the child's life.
- If the child has presented him/herself within 72 hours of being sexually abused, post-exposure prophylaxis (PEP) should be a priority.
- HIV knowledge: establish what the client knows about HIV and AIDS
- Outline the purpose of testing and go through the procedures as well as how to interpret the test results. Explain the window period if it is relevant to the method of testing and age of the child.
- Explore the client's level of risk of HIV infection. This will be linked to the mode of transmission relevant to the particular client.

- Explore and discuss the advantages and disadvantages of testing.
- Find out who the client has told about his/her decision to have an HIV test.

4.4 Explore possible feelings about test results

- Explore feelings about a negative or positive result.
- Discuss the advantages and disadvantages of disclosing or not disclosing.
- Explore support options if test results are positive and/or negative.
- Explore the possibility of suicide if this is mentioned by the client. Defer testing if the risk is high. This might be more appropriate when counselling an adolescent.

4.5 Discuss ARVs and living positively

- Explain that if test results are positive, there are a number of different things that can be done to support a person living with HIV and AIDS to live a normal life. These options need to be relevant to the client. They include:
 - Talking to a counsellor
 - Acceptance of one's status
 - A balanced diet
 - Exercise
 - Sufficient sleep
 - Reducing the consumption of alcohol, tobacco and drugs

- Stress management
- Building self-esteem
- Safe disclosure – telling people you know you can trust
- Learning more about HIV and AIDS
- Planning for the future
- Regular clinic attendance
- Treatment of STI's
- Immune boosters/supplements (under medical supervision)
- Referral and support
- ART when needed.

5. Helping the client make a decision about testing

- Explore the readiness to test
- The caregiver will have to sign a consent form for a child under the age of 12.
- Explain how and when contact will be made with the client following the test.
- If the caregiver or adolescent decides not to have the test, it is his/her right. S/he should be encouraged to take time to think about testing in the near future.
- Pre-test counselling can be provided again or on request.
- Make a referral to a social worker if you think the client needs further assistance in order to deal with barriers to testing.

- Acknowledge the client's courage in making a decision to have the test and highlight the advantages of knowing one's HIV status.

6. Key Resources

1. Children's Rights Centre. 2007. *My Living Positively handbook*. Jacana Media. Johannesburg.
 - This resource is a work book for children living with HIV and AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, talking about HIV, discrimination and adherence.
 - Contact details for Children's Right Centre 031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za.
2. Ramsden,N & Vawda,C. 2007. *You and Your Child with HIV – Living Positively*. Children's Right Centre.
 - This book is included in this package. It is aimed at caregivers of children living with HIV. It includes medical information related to testing, treatment, living positively and referral contacts.
 - Contact details for Children's Right Centre 031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za.
3. Teddy Bear Clinic & Cadre. 2003. *Pre and Post testing counselling Guidelines for counselling*, Department of Health, South Africa.
 - There is also a similar set of guidelines for parents of children who have been sexually abused.
 - see Cadre website www.cadre.co.za.
4. The Adherence Network Group. 2006. *Kids Count – Children's ART Adherence Pack*,. Adherence Network Group. South Africa.
 - The pack is aimed at health care workers and provides in-depth information and offers ideas for practical ways of addressing the key issues related to adherence. Some of these issues include VCT, disclosure, grief, sexuality, parenting challenges and creating effective support strategies.
 - Contact details: The pack can be downloaded from the Perinatal HIV Research Unit's website. www.phru.co.za.

Theory to Practice Card Number Six: Post-Voluntary Counselling and Testing guidelines

1. Background

This process of post-VCT involves telling a caregiver (in the case of a child under 12 years) or an adolescent the result of the HIV test. It is important not to rush through this process. You, the health care worker, have to be aware at all times of the emotional impact that learning about the result of the test is likely to have on your client. This is particularly true when the result is positive.

2. Objectives

- This card outlines some of the main steps that health care workers need to go through when sharing an HIV test result with a caregiver or adolescent.

3. Key terms

3.1 Post-Voluntary Counselling and Testing:

The counselling that is offered to a person after she or the child in her care has undergone an HIV test.

4. Key actions for health care worker

4.1 Getting prepared

- You need to collect the results and confirm with the doctor that they are accurate. This helps avoid possible errors and also gives you an opportunity to prepare for the session with the client

4.2 Introduce session and share results

- If the child is under the age of 12 years, you will first disclose results to an adult caregiver. The child must be outside the counselling room at this time, usually with other children or with one of the members of the health care team.
- Introduce yourself to the caregiver if you were not the counsellor who did the pre-test counselling interview.
- Discuss confidentiality. Explain that the result might need to be known by other members of the team as all the team members work together to support the child.
- Check if the caregiver is the same caregiver who attended the pre-test counselling session.
- Find out if the caregiver is ready to hear the result. Do this even if the result is negative. Say that you ask everyone this question. If the caregiver is not ready to hear the results, the counsellor will need to give the caregiver more time to discuss her fears and feelings.
- Establish what your clinic/hospital's protocol is regarding the disclosure of test results. In some health centres, the counsellor reveals the results while in others the caregiver might be asked to read the result of the test herself.
- Give the test results in a clear and calm manner.

People will be anxious and may have waited for a considerable length of time for the results.

- Do not attach a value judgement to the result, such as "I have good/bad news ...", rather say something like: "the child's test result is positive. This means that he/she has the HI virus in his/her body", or: "the result is negative. This means that s/he does not have the HI virus in his/her body"
- If the child is older than 12, you will have to disclose the results to the child (adolescent)
- If the adolescent is accompanied by a caregiver, you should first discuss the legal age of consent and offer him/her individual counselling. It is important, however, to also encourage older children to involve members of his/her family in the process of post voluntary counselling and testing.
- Follow the points in section 4.2 above, making the necessary adjustments.

4.3 Check the client's understanding of the results and discuss the window period

- Ask the caregiver or adolescent what they understand by the result of the test.
- Clarify any misconceptions.
- Explain the possibility that the child/adolescent might

be in a window period.

- Assess the need to return for re-testing following the window period.
- Reinforce the importance of a re-test.
- Explore precautions and safer sexual practices where appropriate, e.g. in the case of a sexually active adolescent. You might need to do a condom demonstration as well as talk about different ways of talking to one's partner about safer sex.

4.4 Giving an HIV-positive result

- Check if the caregiver/adolescent wishes to know the result of the test. Try to find out their reasons if they do not wish to know it. Their decision must be respected, though. Provide the results in a clear and professional manner if they want to know them.
- Wait for their response.
- Check the caregiver's/adolescent's understanding of the results.
- Respond to the caregiver's /adolescent's feelings and acknowledge what they are going through.
- Identify the caregiver's/adolescent's immediate concerns. Brainstorm all the possible options available to him/her.
- Assist the caregiver/adolescent to think of alternative options and encourage the him/her to come up with his/her own solutions. This may take more than one session.

4.5 Disclosure

In the case of a child under the age of 12

- Explore the caregiver's feelings about disclosure to the child.
- Discuss the advantages and disadvantages of disclosure for the child and caregiver.
- Discuss the possibility of disclosing the child's status to others (other family members or the principal of the child's school, for example).
- Explore different ways of disclosing to the child if the caregiver chooses to do this. These should be based on what is age appropriate for the child. (See page 58)
- If the caregiver chooses NOT to disclose to the child, explore her feelings and thoughts about when it would be appropriate to do so. If the child is currently sexually active, the importance of disclosure and safe sexual practices must be highlighted.
- Devise a long-term plan if the caregiver decides not to disclose to the child at this stage. (See pages 57 and 58)

In the case of a child over the age of 12:

- Explore the consequences of disclosure. Discuss disclosure to people the client trusts, such as partners, family, friends, classmates and health care providers. If a violent or negative reaction from the client's social environment is anticipated, explore "safe disclosure" plans with the client.
- Assess if there is a suicide risk. If there is, conclude a

verbal or written 'suicide contract' with the client in terms of which he/she agrees not to harm him/herself but undertakes rather to first seek help from you or an alternative source of support.

4.6 Living with HIV and AIDS

Explore the various options for living positively

- Diet and nutrition
- Lifestyle (exercise, stress management, spirituality)
- Provide information about support groups
- In the case of children under 12, stress that the caregiver's attitudes and beliefs about the meaning/ implications of being HIV positive influence the ways in which the child will respond to being HIV positive.

4.7 Treatment

Explain the need for ongoing health checks:

- Explain CD4 T-cell counts and viral load tests.
- Discuss long-term scenarios.
- Assess the child/adolescent's family's situation and the accessibility of available treatments such as ART and symptom management.
- Discuss the need for ARVS and adherence counselling.

4.8 Risk reduction

In the case of a child under the age of 12:

- Assess the caregiver's response to the situation, remembering that they might themselves have transmitted the virus to the child.
- It is essential that you avoid blame and judgment. In the case of a vertical transmission, encourage the mother to go for an HIV test in the interest of her own health.

In the case of a child over the age of 12:

- If sexual abuse has occurred, make sure that the child receives further counselling and support
- If the adolescent is sexually active, it is necessary for him/her to understand that re-infection can occur during unprotected sex. This will make it more difficult to treat opportunistic infections.

4.9 Follow-up

Discuss a comprehensive follow-up plan:

- Medical follow-up: emphasise to the caregiver/adolescent the importance of taking prompt action with regard to the treatment of symptoms.
- Discuss how the caregiver can be involved in educating the child about safer sexual practices if the child is sexually active. This will be more effective if done within the context of disclosure.
- Ongoing counselling. The client may be referred elsewhere if there are insufficient resources (for

example, time, skill, knowledge) within your centre.

- Discuss the possibility of joining or establishing a support group.
- Make sure that the client is receiving supportive counselling if necessary

4.10 Giving a negative result

Introduction and sharing of results:

Explore feelings

- Wait for the caregiver/adolescent's response. These might include relief, happiness, continued worry or disbelief. Allow time for the venting of feelings.
- Explore reaction.

Check what the caregiver/adolescent understands by the result

- Make sure the client understands the result.
- Use open-ended questions.
- Remind the client about the window period and the need for re-testing in 3 months

Risk reduction (this will differ depending on the client and the mode of transmission)

- Emphasise preventative measures such as PMTCT, exclusive breastfeeding, treating of sexually transmitted infections, testing and safe sex practices.

5. Key Resources

1. Children's Rights Centre. 2007. *Helping Children Living with HIV*. Jacana Media. Johannesburg.
 - This resource is a work book for children living with HIV and AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, talking about HIV, discrimination and adherence charts.
 - Contact details for Children's Right Centre 031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za.
2. Ramsden, N & Vawda, C. 2007. *You and Your Child with HIV – Living Positively*. Children's Right Centre.
 - The book is included in this package. It is aimed at caregivers of children living with HIV and AIDS. It includes medical information relating to testing, treatment, living positively and referral contacts.
 - Contact details for Children's Right Centre 031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za.
3. Teddy Bear Clinic & Cadre. 2003. *Pre and Post testing counselling Guidelines for counselling*. Department of Health. South Africa.
 - This booklet can be downloaded from the Cadre website www.cadre.co.za. There is also a similar set of guidelines for parents of

children who have been sexually abused.

4. The Adherence Network Group. 2006. *Kids Count* – *Children's ART Adherence Resource Pack*. Adherence Network Group. South Africa
 - The pack is aimed at health care workers and provides in-depth information and practical ways of addressing the key issues related to adherence. These issues include VCT, disclosure, grief, sexuality, parenting challenges and creating effective support strategies.
 - Contact details: The pack can be downloaded from the Perinatal HIV Research Unit's website.
www.phru.co.za



Theory to Practice Card Number Seven: Understanding the importance of disclosure and preparing caregivers for disclosure

1. Background

In most instances, caregivers are reluctant to disclose either their own HIV-positive status or the child's HIV status to the child. There are a number of reasons for their reluctance. This card addresses ways of overcoming the barriers to disclosure and suggests ways of helping caregivers prepare to disclose to their children or to other relevant people that they trust.

2. Objectives

- To help the health care worker assist the caregiver see the importance of disclosure so that he/she can find the courage to tell the child about the child's HIV-positive status
- To help the health care worker help an HIV-positive caregiver to see the advantages and disadvantages of disclosing his/her own status to people whom he/she trusts and feels need to know it as well as to explore whether he or she wants to disclose to his or her children
- To encourage a problem-solving approach with the caregiver. The health care worker needs to ask open questions and elicit responses from the caregiver rather than give all the "answers"

3. Key terms

Disclosure means telling other people about your /their HIV status

4. Key actions for the health care worker

4.1 Explore the meaning and feelings about disclosure with the caregiver:

- Find out from the caregiver what he/she feels about disclosure. It is important to show the link between feelings about disclosure and feelings about HIV and AIDS.
- Different people react differently when they discover their HIV-positive status. One person, might, for example, feel like a passenger who has no control over the vehicle in which they are riding while another might feel more like a driver who is in control over what he/she is doing. (REPSSI 2007d: p31)
- Explain that your role is to help the caregiver feel more like a driver who is in control of the situation. Ultimately it is the caregiver's own decision about whether or not to disclose either his/her own HIV status or the HIV status of the child. This decision will be respected.

4.2 To help a caregiver explore the advantages and disadvantages of disclosing his/her HIV status to a child

- Help the caregiver see the advantages and disadvantages of disclosure: Ask the caregiver to think of the advantages and disadvantages of telling children about his/her HIV status. You could suggest that he/she makes a list comparing the different choices.
- If the caregiver is not able to come up with his/her own reasons for disclosing or not disclosing to a child you could discuss the statements that appear in the table with him/her.

Why I should disclose to my children	Why it's difficult for me to disclose to my children
I would rather the child hears it from me than from someone else. I can decide what to say and I can reassure him/ her.	I have not told others and I'm worried that my child will tell others.
The child might already know something, either by picking up signals or from other people.	I do not want to worry my child.
I know I should begin to talk about this but I have been avoiding the subject because it is difficult and awkward.	I do not know the impact this would have on the child.
As adults, we need to help children talk about their fears and feelings.	I think it will harm the child.
I want my children to know about the modes of transmission of HIV from me so that they do not contract HIV as I did.	I think my child might reject me.
The child may need to prepare for the consequences of my illness (sickness, painful procedures, discrimination and death) and also protect him/herself from becoming infected.	
Research has shown that disclosure to children helps both parents and children psychologically.	
My children could help me with adherence to my medicines if they know about why I need to take these.	
Although I feel guilty, I need to keep telling myself that this illness is not my fault.	

(REPSSI.2007c.p34)

4.3. Explore the caregiver's fears about disclosing his/her HIV status to the adults in his/her life. (You could use the same process as 4.2.)

- Here is a summary of some of the pros and cons of disclosing to other adults:

Why I should disclose to the adults in my life	Why it's difficult for me to disclose to the adults in my life
I feel I have nothing to be ashamed of.	I feel it is my business and a private issue.
I need the support of others in order to follow my treatment properly. It is more difficult to keep taking my ARVs in public when I have not disclosed.	I am afraid of people's reactions towards me. I am afraid of losing my job and that my partner might leave me.
By disclosing, I can share knowledge on issues regarding HIV and AIDS and dispel myths and misconceptions.	People might reject me.

(REPSI.2007c.p34)

4.4 Weighing up the choices:

- The caregiver's readiness to disclose should be assessed.
- Don't rush the caregiver. Disclosure is a process, not a once-off event.
- Remind the caregiver of the importance of counselling. A good counsellor can support and reassure them.
- Plan how, when where and to whom you are going to disclose.
- Identify support – (church, support groups, counselling organisations).
- Once the caregiver has decided to disclose to the child, it might be easier for them to first tell someone close to them whom they you can trust.
- The caregiver needs to take care of herself. Help her find positive ways of coping with stress and anger.

5. Key Resources

1. Children's Rights Centre. 2007. *My Living Positively Handbook*. Jacana Media. Johannesburg.
 - This resource is a work book for children living with HIV and AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, talking about HIV, discrimination and adherence.
 - Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za .
2. Children's Rights Centre. 2007. *A companion book to use with the children's book, My Living Positively Handbook*. Jacana Media. Johannesburg.
 - This resource provides a step-by-step approach for using the hand-book with a child.
 - Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za .
3. Ramsden, N & Vawda, C. 2007. *You and Your Child with HIV- Living Positively*. Children's Rights Centre.
 - This book is included in this package. It is aimed at caregivers of children living with HIV and AIDS. It includes medical information related to testing, treatment, living positively and referral contacts.
 - Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za .
4. Balkwill, 2005. *You, Me & HIV*. Cold Spring Harbour Press, US.
 - This book provides scientifically accurate information about HIV and AIDS, the immune system, prevention and treatment and ways of supporting people with HIV/AIDS. It is accompanied by an educator's guide which includes a range of participatory activities to use with children and adolescents.
 - Contact details: Linzi Rabinowitz at lrab@polka.co.za
5. Flanagan, W. 2003. *I am HIV-Positive*. Heinemann. Johannesburg.
 - This book tells the story of a young girl who is HIV positive and the challenges she faces and overcomes.
6. HIVAN. 2007. *HIV/AIDS, Children's Resource Book Series, No 1*. HIVAN.
 - This resource was created by a group of children living with HIV and AIDS. It covers the following topics: diagnosis, disclosure, treatment, adherence and nutrition.
 - Contact details: HIVAN, The Centre for HIV/AIDS Networking, 031 260 3052 (tel) admin@hivan.org.za.
7. REPSSI. 2007c. *Memory Box Manual*, REPSSI. Johannesburg.
 - Memory boxes and books are used for people (adults and/or children) to tell their life stories in a new and empowering ways. Written prompts are used to help individual select positive narratives about their lives which make them feel better and stronger, and as hopeful and as proud of their life as they possibly can be. Memory books/boxes can be used as a tool to facilitate conversations between parents and children, particularly with regard to disclosure and planning for the future.
 - Contact details: This resource can be downloaded from the REPSSI website, www.repssi.org.
8. Soul City. 2003, *HIV and AIDS affect all children*. Jacana Media. Johannesburg.
 - Soul City offers a wide range of health-related booklets including topics such as HIV/AIDS, Social Grants, Health lifestyle issues. Booklets are aimed at young people, parents, health care workers and teachers.
 - Contact details: 0860115000, website www.soulcity.org.za

Theory to Practice Card Number Eight: Guidelines for telling a child about the child's HIV status

1. Background

Once caregivers have been able to see the benefits of telling a child about the child's HIV status, they will need support in finding ways to actually disclose to the child. It is important to give them the opportunity to think about what they would say and how they would say it.

2. Objectives

- To help health care workers guide caregivers to find practical ways of talking to their children about their HIV status.

3. Key actions for health care worker and caregiver

3.1 Check to see if the caregiver is ready to disclose to his/her child:

- Talk about the courage that is needed tell a child that they are HIV positive. It can be very hard, awkward, embarrassing and exposing. Point out that despite these difficulties it is best to tell the truth. Children will in any case try to work things out on their own. Their rich imaginations often lead them to think the worst.
- Help the caregiver identify ways of preparing him/herself for the disclosure:

- Recommend certain books that might help the caregiver communicate a specific message to the child
- Encourage the caregiver to practice the disclosure session with you or with someone else she trusts. This will help her to feel confident and positive during the actual process of disclosing to the child.

3.2 Help the caregiver prepare for the disclosure

Help to plan what the caregiver will say using the caregiver's knowledge and sensitivity as the basis of the disclosure.

- Ask the caregiver to think about how he/she might disclose the child's HIV status to the child
- You could ask the caregiver to write these thoughts down on paper or just tell them to you.
- This process can also be followed in the context of a support group. The caregiver could also discuss how she would disclose to other people besides the child herself.
- Discuss what is helpful about the way the caregiver plans to disclose to the child and what is not.
- Where appropriate, the health care worker can go over the guidelines in 3.3 below with the caregiver.

3.3 Some basic guidelines when telling a child about his/her HIV status

- Always keep in mind the personality and situation of a particular child
- Remember there is no blueprint that covers all children and all situations. The individual child's needs and the nature of the relationship between the child and the caregiver will need to be taken into account
- Use language that is appropriate to the child's developmental level, level of education and emotional readiness.
- Create a climate in which the child will feel free to ask questions. Try not to avoid the questions that the child may ask.
- Make sure that the disclosure is part of an ongoing conversation about health
- Emphasise that HIV is a common chronic illness like asthma and diabetes. It is not curable but it can be treated. It is not a death sentence
- Make sure you are in a quiet place without any interruptions
- If you do not know the answers to all the child's questions, undertake to find them

3.4 Anticipate and plan how to respond to possible responses (verbal and non-verbal) of the child.

Some possible questions and answers might include:

How did I get it? *"Let's talk (or read) about the ways children can get HIV and then talk about how you got it?"*

Do you have it? *"Yes, I have it too, just like you! I am also taking medicines and looking after my health."* or *"NO, I do not have HIV."*

Where did you get it from? You could say, *"This is a private matter and I am not ready to talk about it "*, or else you could be open and say (to an older child), *"I got HIV through sex. When you are older, we will talk more about this. When you are ready to have sex, you must speak to me first so that I can teach you how to keep yourself and your partner safe from HIV."*

Why must I take medication? *"The medicines help you stay strong and well."*

Can I stop taking medicine? *"You will need to take medicines until the doctors find other ways of helping your body to live with HIV."*

Will I be sick forever? *"There is no cure yet. HIV will live in your body forever, but this does not mean you will always*

feel sick. We must help to keep your body strong so that you will feel well most of the time. You can take medicine, visit the clinic, eat healthy foods and keep clean. Remember, we will always love and support you. "

Will I die? (The feeling behind this question is fear and confusion. It is important to respond appropriately) *"With this medication, you can live a long, long time. There are special doctors and scientists who are looking to find ways of fighting the HI virus. Death is a scary thought. We all die one day. But if you take this medication, you will probably live a long time."*

Who can I tell? *"Having HIV is not a bad or a shameful thing, but it is a private thing. You can talk to me, your father, nurses, counsellors and other HIV-positive children at the clinic".* Help your child feel free to talk at any time about any unkindness they may experience themselves or witness someone else experiencing. Ask your child for ideas about what he would like to say or do if he was treated unkindly. Make sure your child knows you are there to give love and support. You could say: *"Not everyone understands about HIV. It is better to talk to people who understand and know the facts. Who would you like to tell and why? What do you want them to know? We might be able to tell them together. When people don't understand, they get scared. Scared people sometimes say hurtful things. We need to choose whom to tell carefully".* (Adapted from

Children's Rights Centre 2007)

3.5. Anticipate and plan for the impact on family members, friends, school and community members

- You need to find out from the child whom he/she would like to tell and why.
- Help the child see that it is only helpful to tell people who will be able to be kind and supportive
- It is important to give the child appropriate and useful information in order to dispel the myths and fears about HIV and AIDS

3.6 Be led by the child (their questions, reactions) about the amount of information to give at a particular time

- Accurate information can be given in response to questions. You do not need to tell everything all in one go. Give your child time to absorb the information.
- Make sure your child has understood the information. You can use drawings to help explain some of the facts.
- Make sure your child feels free to ask questions.

3.7 Keep what is said simple, clear and honest

3.8 Remember that children often believe that illness is their fault. They might have to be reassured that are not ill because they have done something wrong.

- Assurance of support and willingness to help should be given

3.9 Need to give positive living messages

- Ways of living positively are more important than concern for the mode of transmission
- Remind them that there are many different ways of looking after themselves. These include eating well, resting, taking medication, and enjoying their friends, family and interests
- Remember that HIV is not the only part of your child's life. Your child's life is bigger than his illness, although the illness is a part of it.

4. The post-disclosure period is critical

Monitor the child's behaviour (sleeping, eating, emotional reactions, school performance). Take action if any negative changes persist for longer than a few weeks.

- Each child will do, say and feel different things after they have learnt that they are HIV positive.
- Remind them that they can talk to you about their fears, feelings and problems whenever they need to.

5. Key Resources

1. Balkwill, 2005. *You, Me & HIV*. Cold Spring Harbour Press. US

- This book provides scientifically accurate information about HIV and AIDS, the immune system, prevention and treatment and ways of supporting people with HIV and AIDS. It is accompanied by an educator's

guide which includes a range of participatory activities to use with children and adolescents.

- Contact details: Linzi Rabinowitz lrab@polka.co.za

2. Children's Rights Centre. 2007. *My Living Positively handbook*. Jacana Media. Johannesburg

- This resource is a work book for children living with HIV/AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, how to talk about HIV, discrimination and adherence
- Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za
and email address info@crc-sa.co.za

3. Children's Rights Centre. 2007. *A companion book to use with the children's book, My Living Positively handbook*. Jacana Media. Johannesburg

- This resource provides a step by step approach for using the hand-book with a child.
- Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za
and email address info@crc-sa.co.za

4. Ramsden, N & Vawda, C. 2007. *You and Your Child with HIV- Living Positively*. Children's Rights Centre

- This book is included in this package. It is aimed at caregivers of children living with HIV. It includes

medical information related to testing, treatment, living positively and referral contacts.

- Contact details for Children's Rights Centre
031 307-6075, website-www.childrensrightcentre.co.za
and email address info@crc-sa.co.za

5. Flanagan, W. 2003. *I am HIV- Positive*. Heinemann. Johannesburg

- This book tells the story of a young girl who is HIV positive. It describes the challenges she faces and overcomes.

6. HIVAN. 2007. *Hi Virus, Children's Resource Book Series. No 1*. HIVAN

- This resource was created by a group of children living with HIV and AIDS. It covers the following topics: diagnosis, disclosure, treatment, adherence and nutrition.
- Contact details: HIVAN, The Centre for HIV/AIDS Networking, 031 260 3052 (tel)admin@hivan.org.za.

7. Soul City Publications

- Soul City offers a wide range of health related booklets on topics such as HIV/AIDS, health and lifestyle issues. Booklets are aimed at young people, parents, health care workers and teachers.
- Soul City Distribution Contact details: 0860115000, website www.soulcity.org.za

Theory to Practice Card Number Nine : Guidelines for Anti-Retroviral Treatment (ART) adherence counselling

1. Background

In order to be most effective adherence counselling should involve both the child and the caregiver or another treatment support person. This is also true in the case of adolescents. The process of adherence counselling is an ongoing one. It needs to be tailored to the particular needs of individual children and their home situation.

2. Objectives

- To give the health care worker an overview of the different aspects involved in the 3 stage adherence counselling model
- To help a child and caregiver who are starting ART to make choices that support their treatment.

3. Key terms

Adherence: “The degree to which a patient follows a treatment regimen which has been designed in a consultative partnership between the client (caregiver/ child) and the health care worker. It encourages discussion about the treatment regimen”. (Adherence Networking Group 2006a: p18)

4. Key actions for health care worker

4.1. Stage I: Pre ART (readiness) assessment and

preparation (2–4 sessions)

The aim of this stage is to establish the full commitment of the child and caregiver to the treatment before starting.

- Introduction to ART
- Explain your role in ART
- Assess the clients' readiness to start treatment
- Ensure confidentiality
- Introduce the treatment and adherence programme
- Introduce medical procedures related to treatment
- Explain the risks and benefits of ART (it is a long term treatment programme, not a cure)
- Complete administration forms
- Sign a commitment form to adhering to treatment
- Medical assessment (this is usually done by a Doctor). It includes:
 - Medical assessment. This consists of compiling a complete medical history of the patient and conducting a thorough physical examination. Tests will have to be conducted to determine the child's blood count, CD4 level, lymphocyte cell count and Viral load. The child's level of growth and development will also be assessed at this stage
 - Mental health assessment(depression, behaviour change etc.)
 - Other routine tests

- An assessment of the psychosocial and physical status of the caregiver
- Explore child's HIV history and home circumstances
- Allow the client to tell their story (the primary client in most instances will be the caregiver unless the child is over 12 and prefers to be seen on his own)
- HIV history (when diagnosed, reasons for testing, mode of transmission: perinatal/breast/ blood/sexual)
- Awareness of HIV status (has the child been told about his HIV status?)
- School attendance and performance
- Caregiver's experience of and views about HIV (feelings about child's status, views on treatment, levels of knowledge, own health status)
- Household composition (primary and secondary caretakers)
- Family history (e.g.: HIV infection of others, deaths, relocations, fostering)
- Material circumstances
- Disclosure
- Assess the caregiver's feelings and attitudes about disclosure
- Consider the child's age and explore the Appropriateness of sharing information with him/her
- If the caregiver has chosen not to disclose, explore

- his/her reasons for non-disclosure
- Assess readiness to disclose
- Explore reactions from family and friends if the disclosure has already occurred
- Facilitate supported & safe disclosure when possible
- Assess factors that influence adherence
- Possible factors that may support or be barriers to adherence.
- The caregiver's lifestyle, personal qualities (discipline, responsibility), daily routines and support network
- Access to treatment and reliable transport (nearest roll-out site, transport, mobile lifestyle, employment)
- Prior medication adherence patterns
- Sources of support (treatment support, support group, buddy system etc)
- Material resources such as adequate nutrition, foster/child care grant, housing, sanitation, domestic violence and trust in the health care team
- Self-care since diagnosis: You need to establish how the caregiver or adolescent looks after the child or him/herself following the diagnosis.
- Attitude towards HIV status
- Dietary patterns and nutrition
- Rest and stress patterns (current routine, life demands and the management of these)
- Treatment and prophylaxis for opportunistic infections
- Substance use/abuse by caregiver/child
- Patterns of sexual behaviour and intimate relationships

- (if the child is sexually active)
- Other medication (immune boosters, alternative/traditional medicines, etc.).
- ART readiness
- Assess caregiver's (or adolescents) motivation for beginning ART
- Assess ability to commit to ART and lifelong treatment
- Explore perceived advantages/disadvantages of being on ART
- Explore emotional responses to possibly starting ART (fears, excitement, hopes).
- Preparation: health care worker will need to explain the following:
 - Outline the medical procedures (such as blood tests)
 - expected changes in physical well being
 - Possibility of side effects (usually not severe in children, generally pass within 1–2 weeks, will need attention if they become serious)
 - Possibility of opportunistic infections. How to recognise and respond to the symptoms of these infections
 - How and when to take medication
 - Importance of adherence and what it involves (tablets taken on time, daily and for life)
 - Consequences of non adherence (treatment ineffective, drug resistance)
 - Reinforce motivation
 - Assist caregiver to obtain necessary support grants

- (child support, disability grant for caregiver if CD4 count is less than 200)
- Explain treatment site procedures and supply information about the location of various services
- Develop specific treatment plan; health care worker and child/caregiver develop plan together
- Treatment regimen (specifics of medication, doses, and the intervals at which they should be taken)
- Possible side effects: what to do and who to contact in case of serious side effects
- Integrate treatment into the daily routine of the child and caregiver
- Individual strategies that conform to the daily routines, basic needs and literacy level of the caregiver
- Provide practical aids and supportive handouts
- Demonstrate dosage and method of administration
- Have caregiver/child demonstrate administration with mock medication
- Review and revise plan if necessary
- Plan follow up (telephone, clinic visit)

2.2.Stage 2: ART initiation and maintenance

The aim of this stage is to support the child in his/her process of adjusting to medication and to address any difficulties that may arise.

- The need for visits
- Need to conduct a follow up within 1–2 weeks of starting ART

- Members of health care team should follow up monthly (coinciding with collection of medication from pharmacy)
- Follow up clinical assessment should take place every 3–6 months
- More frequent visits or contact may be required in early stages of ART or in the event of side effects or opportunistic infections.
- Initiate treatment
- Treatment regimen given to caregivers
- Integration into daily routine
- Reminder about practical aids
- Demonstrate dosage and method
- Mention simple remedies for mild side effects. Supply information about whom to contact in the case of more serious effects
- Plan the follow up
- Give contact details
- ART monitoring
- Medical component: examinations should be conducted that take into account prior medical conditions, the history of reported adherence, possible side effects, recent illnesses, current clinic situation, evidence of progression, evidence of immune reconstitution disease, evidence of toxicities
- Adherence patterns: report non-adherence, review support strategies, assess implication of CD4% and viral load

- Factors influencing adherence: explore issues arising since starting ART such as difficulties with adherence, changes in routine, effects of medication, changes in home life, access to site (see previous section on factors influencing adherence)
- Self care since starting ART: explore factors that have or may become barriers to adherence and discuss ways to deal with them. These might include dietary patterns, insufficient rest and too much stress (see previous section about self care)
- Caregiver/child's experience of ART adherence support.

Stage 3: Re-motivation and/or treatment change

The aim of this stage is to assess the effects of treatment and the need to revise /re-emphasise the reasons for adherence.

- Assessment
- Indications of persistent non-adherence
- Persistent side effects or toxic reactions
- Clinical signs of treatment failures
- Laboratory indication of resistance to ART or its failure.
- Re-motivation, as for stage 1 (including re-education HIV/AIDS, ART if necessary) treatment change
- Educate caregiver about new regimen
- Discuss possible side effects,
- Emphasise adherence
- Reinforce the message that treatment is life long

- Help strengthen the commitment of both the caregiver and the child.

5. Key resources

1. REPSSI & Catie. 2008. *Tracing Book and Treatment Information Manual – scaled down body maps as a tool for tracking and communicating biomedical and psychosocial HIV wellness and illness*. REPSSI. Johannesburg.
 - This uses a variation of the body mapping activity. A scaled-down body map is used to help young people track their health and illness. It can assist patients to accept more responsibility for aspects of their illness such as treatment literacy, adherence, disclosure and communication.
 - This resource is available from REPSSI. Contact details. 011 9985820 or www.repssi.org
2. Children's Rights Centre. 2007. *My Living Positively Hand Book*. Jacana Media. Johannesburg.
 - This resource is a work book for children living with HIV and AIDS. It addresses a number of topics including HIV transmission, understanding HIV, how to live positively, how to take medicines, how to talk about HIV, discrimination and adherence.
 - Contact details for Children's Right Centre 031 307-6075, website-www.childrensrightcentre.co.za and email address info@crc-sa.co.za .

3. Children's Rights Centre. 2007 *A companion book to use with the children's book, My Living Positively Handbook*.

Jacana Media. Johannesburg.

- This resource provides a step-by-step approach for using the hand-book with a child.
- Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za
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4. Ramsden,N & Vawda,C. 2007. *You and Your Child with HIV-Living Positively*. Children's Right Centre

- This book is included in this package. It is aimed at the caregivers of children living with HIV and AIDS. It includes medical information related to testing, treatment, living positively and referral contacts.
- Contact details for Children's Right Centre
031 307-6075, website-www.childrensrightcentre.co.za
and email address info@crc-sa.co.za.

5. The Adherence Network Group. 2006. *Kids Count–Children's ART Adherence Resource Pack*. Adherence Network Group. South Africa.

- The pack is aimed at health care workers and provides in-depth information and practical ways of addressing the key issues related to adherence. Some of these issues include VCT, disclosure, grief, sexuality, parenting challenges and creating effective support strategies.
- Contact details: The pack can be downloaded from

the Perinatal HIV Research Unit's website.

www.phru.co.za

Check-list Number Four: Pre and Post VCT

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
Understanding the role of VCT in the prevention and treatment of paediatric HIV and AIDS	Read key points on Voluntary Counselling and Testing	<ul style="list-style-type: none"> • Build a supportive relationship with the caregiver • Encourage the caregiver to make a decision that is in the best interests of his/her child 	If age appropriate, encourage the child to make a decision that will be in his/her best interests	See page 50
What does the health care worker need to know about VCT?	<ul style="list-style-type: none"> • Know the national guidelines for age of consent • Be up to date and familiar with different ways of testing different age groups of children for HIV (children) and when to apply these tests • Identify children who should undergo an HIV test 	<ul style="list-style-type: none"> • Share this information with the caregiver • Give the caregiver time to absorb all new information • Allow the caregiver to ask questions 	<ul style="list-style-type: none"> • Share this information with the child • Encourage the child to seek support from a caregiver/family/friend 	See pages 51 – 53
What is the role of the health care worker?	In order to actively prevent MTCT and to promote and initiate early and effective treatment for children living with HIV and AIDS, you need to encourage caregivers to test children at risk of HIV infection.	<ul style="list-style-type: none"> • Create a safe and supportive relationship with the caregiver • Share information appropriately to the needs of the caregiver • Help caregiver understand what is in his/her best interests for his/her child 	<ul style="list-style-type: none"> • Create a safe and supportive relationship • Encourage child to ask questions 	<ul style="list-style-type: none"> • See Theory to Practice Card 5: Pre-Voluntary Counselling and Testing guidelines • See pages 50 and 51

TABLE CONTINUED ON NEXT PAGE

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
What is VCT?	Read section on the purpose of VCT	<ul style="list-style-type: none"> • Build a positive relationship with the caregiver • Do not judge the caregiver if he/she does not give consent for an HIV test • Focus on helping the caregiver address his/her fears about testing • Find ways to normalise HIV and AIDS 	<ul style="list-style-type: none"> • Build a positive relationship with the child • Do not judge the child if he/she is not ready to consent to an HIV test 	<ul style="list-style-type: none"> • See Theory to Practice Card 5: Pre-Voluntary Counselling and Testing guidelines • See Theory to Practice Card 7: Understanding the importance of disclosure and preparing caregivers for it
What is pre-VCT counselling?	Read Section on Pre-VCT counselling	<ul style="list-style-type: none"> • Adapt and use the guidelines on Theory to Practice Card 5 • Acknowledge the caregiver's courage for seeking VCT 	<ul style="list-style-type: none"> • Adapt and use the guidelines on Theory to Practice Card 5 • Acknowledge the child courage for seeking VCT 	Read Theory to Practice Card 5: Pre-VCT guidelines
Who does the health care worker counsel?	Read section on VCT for children under and over the age of 12	<ul style="list-style-type: none"> • Counsel the caregiver in situations where children are under the age of 12 	<ul style="list-style-type: none"> • Counsel a child over 12 on his/her own, but where possible include a caregiver • Assess the emotional maturity of the child 	See pages 50 – 52
What is post-VCT counselling?	Read Theory to Practice Card 6: Post-Voluntary Counselling and Testing guidelines	Adapt and use the guidelines on Theory to Practice Card 6	Adapt and use the guidelines on Theory to Practice Card 6	Read Theory to Practice Card 6: Post-Voluntary Counselling and Testing guidelines

Check-list Number Five: Disclosure

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
What is disclosure?	Read the key points on disclosure	<ul style="list-style-type: none"> Select points which are appropriate to the caregiver Show empathy and support 	<ul style="list-style-type: none"> Show empathy and support Consider what is age appropriate and in the best interests of the child 	See pages 53 – 54
What is the role of the health care worker?	<ul style="list-style-type: none"> Read the section on the role of the health care worker and understanding disclosure and its importance in the role of effective treatment Be aware of your own feelings about disclosure 	Support the caregiver by patiently helping him/her identify and address his/her fears about disclosure	Support the child by patiently helping him/her identify and address his/her fears about disclosure as well as his/her feelings about being HIV positive	See page 54
What are the obstacles to disclosure?	Read the section on disadvantages for the caregiver and the child, factors that prevent disclosure and beliefs and attitudes about what is best for children	<ul style="list-style-type: none"> Support the caregiver by helping them identify their fears Show respect and patience 	<ul style="list-style-type: none"> Support the child by helping him identify his fears Show respect and patience 	See pages 55 – 57
What are the benefits of disclosure for the child and the caregiver?	Read the section on benefits for the child and benefits for the caregiver	Help the caregiver identify their fears and weigh up the options	Help the child identify their fears and weigh up the options of telling others about his/her HIV positive status	<ul style="list-style-type: none"> See pages 54 – 55 See Theory to Practice Card 7: Understanding the importance of disclosure and preparing caregiver for it

TABLE CONTINUED ON NEXT PAGE

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page
What are the different phases of preparing to disclose?	<ul style="list-style-type: none"> • Read the section on the process of disclosure • Acknowledge that caregiver needs time to prepare for the process of disclosure • Identify the phase that the caregiver is in en route to disclosure 	Share this information with the caregiver and allow him/her to work through these different stages	Share this information with the child and allow him/her to work through these different stages	See pages 57 – 58
What are the general guidelines for disclosure?	Read the section on general guidelines for disclosure	Select and adapt guidelines to share with the caregiver	Select and adapt guidelines to share with the caregiver	See pages 57 – 58
What are the age-specific guidelines for disclosure?	Read the section on specific guidelines for different age groups.	Find out from caregiver how she would disclose to a child	Select and adapt information for the child.	<ul style="list-style-type: none"> • See Theory to Practice Card 8: Guidelines for telling a child about the child's HIV status • See pages 58 – 59
How to disclose?	Read Theory to Practice Cards 7 and 8	<ul style="list-style-type: none"> • Select and adapt key actions with the caregiver • Role play disclosure if necessary with the caregiver 	Select and adapt key actions with the child	See Theory to Practice Card 8: Guidelines for telling a child about the child's HIV status

Check-list Number Six: ART adherence counselling

Topic	Action by health care worker	Action by health care worker with caregiver	Action by health care worker with child	Page and Section
What is adherence?	Read the following sections: key points, assessing adherence and understanding adherence	Maintain a caring and supportive relationship with the caregiver	Maintain a caring and supportive relationship with the child	See pages 59 – 60
What are some of the reasons for non-adherence?	<ul style="list-style-type: none"> • Read the section on Non-adherence • Read chapter on disclosure 	Avoid blame and rather problem solve together with the caregiver	Avoid blame and rather problem solve together with the child	<ul style="list-style-type: none"> • See page 62 • See Theory to Practice Card 7: Understanding the importance of disclosure and preparing caregivers for it
How to widen the circles of support ?	Read the section on circles of support	Share contacts with the caregiver	Share contacts with the child	See pages 60 – 61
What is adherence counselling?	Read sections on Knowing the medical facts and assessing adherence, general principles for adherence counselling and the health care team	Maintain ongoing contact with the caregiver	Maintain ongoing contact with the child	<ul style="list-style-type: none"> • See pages 62 – 63 • See Theory to Practice Card 9: Guidelines for Anti-Retroviral Treatment (ART) adherence counselling
What are the general and specific medication factors to consider in adherence counselling?	Read the section on general principles of adherence and how can we support caregivers in helping children adhere to their medication	Select appropriate information and share this with the caregiver	Select appropriate information and share this with the child	See pages 62 – 65
What is the three-stage adherence counselling model?	Read the section on the three-stage adherence counselling model	Take the caregiver through this process without rushing	Take the child through this process without rushing	See Theory to Practice Card 9: ART adherence counselling

Appendix One: Outline of Developmental Stages from Birth to Adolescence: Parent Centre's Parenting Programme 2007

Note: Our primary task as caregivers is to provide responsive and predictable emotional and physical care.

Stage 1: Birth to 18 months: Trust vs. Mistrust

Babies learn and grow very quickly at this stage. They need to learn to trust. The relationship that they have with their primary caregiver (usually the mother) forms the basis of their sense of security and ability to trust for the rest of their lives. It is the time in which they learn to trust the world and experience it as a safe and caring place. Children cannot deliberately misbehave at this age. Their behaviour is merely their way of communicating their needs and discomforts. A baby can never have too much love or affection.

Stage 2: 18 months to 3 years: Autonomy vs. Dependence

Children of this age are learning to be independent. They assert their emotional separateness by asserting their wishes. They begin to learn to do things for themselves. They also learn to get along with their peers. They do not want to be controlled and continually test the power of "NO". Although it can be very trying to caregivers, children's negativity

and wilfulness should not be interpreted as naughtiness or stubborn behaviour. It is part of the child's natural and healthy attempt to achieve autonomy.

Caregiver's role

Our primary task as caregivers is to provide a secure and safe environment in which language and social skills can be acquired and developed. We need to have realistic expectations of the child and allow him/her to make mistakes. NO's should be kept to a minimum. Caregivers can best help their children at this stage by avoiding direct orders and encouraging co-operation through giving them appropriate choices. It is also helpful to acknowledge and accept children's feelings while at the same time limiting unacceptable behaviour. This is the beginning of the separation process that continues throughout life.

Stage 3: 3 to 6 years: Initiative vs. Guilt

This stage is marked by an overwhelming drive to play and explore. Children of this age need to express their creativity and feel competent. They are learning to master the world around them. They experience a great deal of intellectual growth, and become more involved with the world around them. They are also learning to have better control of their bodies. They need to engage in lots of physical play.

Caregiver's role:

Our primary task as caregivers of children at this stage of their lives is to encourage their attempts to try new things. Encourage them to show initiative. Believe in their ability to succeed. The focus should be on building their self-esteem. They should be allowed to fail and to try again. Any mistakes they make at this stage are good opportunities for learning. At the same time, children of this age begin to become aware of the process of socialisation. They realise the need to co-operate and know when they are not being cooperative.

Stage 4: 6 to 12 years: Industry vs. Inferiority

The world expands for children of this age through their interactions with peers and teachers. They learn by doing. They become more and more capable intellectually. They learn values through what they experience at home.

Caregiver's role:

Caregivers should show that they trust their children. They should be given increased responsibility, but within reason. Friendships and activities outside of the home should be encouraged.

Stage 5: 13 to 21 years: Identity vs. Identity Confusion

Adolescents are looking for a sense of identity. Although they are preoccupied with themselves, they also have an awareness

of the social world around them. Their peer group is very important. Their sexuality awakens. This results in dramatic hormonal and physical changes and powerful feelings, which can cause anxiety. Although they are becoming physically mature, they are not yet emotionally mature. They often struggle for their independence.

Caregiver's role:

Caregivers need to start granting teenagers autonomy, while still providing the emotional care and security that they need. In South Africa there is a very real conflict between allowing independence and being careful about children's safety.

Caregivers need to provide guidance, but teenagers need to do things for themselves.

Appendix Two: Age-specific perceptions about death adapted from Mallman (2002), ANECCA (2006) and The Adherence Networking Group (2006)

Age of child	Understanding of death and possible reactions	Ways of responding to child
Birth to 3 years	<p>Babies and toddlers have very little understanding of what death means</p> <p>The death of a close caregiver is experienced as a separation from that person. The child might even feel abandoned. They miss the person and may look for her or ask repeatedly where she is.</p> <p>They are unable to talk about what they are feeling directly. They show their feelings through their behaviour. They may cry a lot, refuse comfort and withdraw and become passive. They may regress in certain ways, have difficulties in sleeping, for example, or develop habits such as thumb-sucking and nail biting.</p>	<p>Caregivers need to be patient with babies and toddlers.</p> <p>Caregivers need to give them a lot of physical affection and comfort</p> <p>Routines should be kept in place where possible. This helps the child feel secure.</p>
3 to 5 years	<p>Death is not seen as something permanent and final. Even when the child has seen the dead person, he/she still does not understand that the deceased is not going to come back.</p> <p>Pre-schoolers tend to link the person's death to themselves. They may see it as a punishment for something they have done or think that they have been abandoned.</p> <p>Children grieve intensely at this age. They may cry or throw tantrums. They might suffer from sleep disturbances or start wetting their beds.</p> <p>Children might be disturbed and confused when adults show emotional distress.</p>	<p>Caregivers need to give lots of physical attention, comfort and affection.</p> <p>It is important to talk to them about death, dying and funerals. Giving answers helps them make sense of the situation.</p> <p>The use of stories and drawings can also help them understand and express what they are feeling.</p> <p>It can take up to two years for a child to recover from the loss of a close family member.</p>

TABLE CONTINUED ON NEXT PAGE

Age of child	Understanding of death and possible reactions	Ways of responding to child
6 to 12 years	<p>Older children are more able to understand that death is permanent and final.</p> <p>They are able to understand the obvious causes of death.</p> <p>They grieve in similar ways to adults. At times, however, they may swing between sadness, anger and indifference.</p> <p>They may exhibit anger and clinging behaviour, and experience physical pains, nightmares and anxiety about others close to them.</p>	<p>Caregivers need to make time to talk about their children's feelings and about what death means.</p> <p>It helps to share memories about the person who has died.</p> <p>It is important for children to play with their friends and be involved in ordinary day to day activities</p>
13 years and older	<p>Adolescents understand that death is permanent and final, They realise that all people die. They usually see their own deaths, though, as distant events.</p> <p>Their understanding of death might make them feel vulnerable since they realise that death is something that is beyond their control.</p> <p>It might be difficult for an adolescent to acknowledge loss and sadness. They need to appear independent. This might make it difficult for them to receive support from family and friends.</p> <p>The death will be especially difficult for the adolescent to come to terms if they learn at the same time that the caregiver died of AIDS or that they themselves are HIV positive.</p> <p>Typical symptoms of grief will include sadness, depression, anger, helplessness emotional pain and longing for the parent. It is common for adolescents to react with denial, delayed reactions and suppression of feelings.</p> <p>As adolescence is a time for experimentation, risk taking might increase. It could take a negative form such as glue sniffing, smoking and drinking.</p>	<p>Caregivers need to involve adolescents in arrangements that are connected to the death.</p> <p>They benefit from the presence of a trusted friend from outside of the family to whom they can express their feelings.</p>

Appendix Three: Dino Feeling Cards

- 1 - OPTIMISM (optimistic, hopeful, positive)
- 2 - MISTRUST (mistrustful, fearful, cautious, confused)
- 3 - ANXIETY (fearful, anxious)
- 4 - REFLECTION (thoughtful, calm)
- 5 - FEAR (afraid, terrified)
- 6 - HAPPINESS (happy, glad, joyful)
- 7 - SADNESS (sad, lonely, depressed)
- 8 - ANGER (angry, cross)
- 9 - CONTENTMENT (relaxed, calm, peaceful)
- 10 - ASSERTION AND SELF PROTECTION (Stop!, No!, Leave me alone)
- 11 - WONDER (curious, interested)
- 12 - SAFETY (secure, protected)



Appendix Four: Training packages and contact details

- 1. Adherence Networking Group:** Children's ART Adherence Resource Pack. A resource designed to strengthen the capacity of those involved in the planning, provision and support of ART interventions with children to facilitate adherence to antiretroviral treatment (ART) (Adherence Networking Group, 2006)
Contact details: Jenny Bowman
Tel: 011 989 9700 Email: bowmanj@hivsa.com
- 2. Paediatric HIV Counsellor Training Package:**
A comprehensive programme designed to enable trainees to provide an effective counselling service to individuals and caregivers who are infected and affected by HIV and AIDS.
Contact details: WITSECHO, Training Department.
Tel: 011 547 5009
- 3. Counselling Training Manual:** A foundation for the above. Not HIV specific but incorporates a generic set of skills that can be used in multiple settings (Adherence Networking Group, 2008)
Contact details: Jenny Bowman
Tel: 011 989 9700 Email: bowmanj@hivsa.com
- 4. Mainstreaming Psychosocial Care and Support within Paediatric HIV and AIDS Treatment:** A four day training course including communication/counselling and Paediatric specific skills in working with individuals, groups and communities. Contact details: REPSSI, Training Manager-Carmel Gaillard
Tel: 011 9985820 Email: carmel@repssi.org

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