

The Rights of Children and Young People in Palliative Care

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Overview of Palliative Care for children

This chapter describes legal rights of children and young persons including their right to palliative care. Children may be affected either as patients receiving palliative care or as family members of palliative care patients.

Definition

Palliative care for children is the active care of the body, mind and spirit of the child with a life-threatening, chronic, life-limiting illness or severe disability, and includes support for the family into the bereavement period. The aim of palliative care is to improve quality of life and relieve suffering. For children this also includes support of optimal childhood development, formal education, and developmental stimulation to enable the child, at any age, to live the best life possible.

What's different about Palliative Care for children?

Just as adults do, children have the right to palliative care. However, children are not merely little adults, so palliative care for children can not be adult palliative care cut down to size. While children are inherently vulnerable and varyingly dependent, they are also inherently capable in different ways at different stages in their lives and in different circumstances. Consequently the realisation of any one child's rights must take into account a number of factors based on the expression and nature of children's vulnerabilities, dependencies and capabilities.

A life-limiting illness such as cancer, AIDS or muscular dystrophy increases the vulnerability of children. It also changes the capacities and dependency of that child. Palliative care services, that reach children in their homes, through day care programmes and in residential care facilities, have the potential to improve the quality of life of these children and those around them with skilled and compassionate interventions.

Children's rights and realities as context

A children's rights approach underlies effective paediatric palliative care programming. The essential requirements of childhood are outlined in children's rights: health care and a healthy environment, parental and family care, education, access to information, participation, play, friends, identity, dignity and protection from harm. Children's rights also address what needs to be done when things go wrong in an individual child's life (loss of parents), or in the world around that child (living in poverty or in war or other conflict). These rights are set out in international documents such as the United Nations Convention on the Rights of the Child (UNCRC) and the African Union's African Charter on the Rights and Welfare of the Child. South African legal protections are entrenched in the Constitution and laws, especially the Children's Act, and

Terms you will read in this chapter:

Advocacy: active vocal support for those who may not have the ability to represent themselves.

Analgesics/Analgesia: medication that relieves pain

Asylum: protection granted by a government to someone who has fled from another country

Cognitive developmental challenges: challenges to develop thought processes and thus acquire knowledge

Disclosure: information that is revealed which has been secret e.g. HIV status

Exemption: permission not to do what others are required to do e.g. exemption from school fees

Historically unprecedented: this is the first time it has happened (no record in history)

Holistic care: care which takes into account all of the patient's physical, mental and social conditions

Jurisdiction: the authority to enforce laws or pronounce legal judgments in a certain area

Muscular dystrophy: a medical condition with gradual wasting and weakening of the skeletal muscles

Succession: inheritance of position or possessions from deceased parents

documents such as the National Strategic Plan on HIV and AIDS and STIs 2007–2011 (NSP).

The guiding principles in realising children's rights are written into South African laws:

- The best interests of the child
- According to need (special provision for special need)
- All rights for all children (equality and non-discrimination)
- Ethical, meaningful child participation in critical areas of their lives including decision-making. The application of these principles in practice, requires adults to be taken into account.
- The whole child
- Each child's individual characteristics (like personality in particular)
- The situation at any point in time *and* their developmental stage
- Uniqueness of each child
- The changing needs, dependencies and abilities of each child

The realities of children's lives in South Africa are that most live in extremely difficult circumstances: in poverty, with many exposed or subjected to violence, abuse, neglect or exploitation; many children living with only one parent or in households headed by a grandparent. On top of this, HIV/AIDS is increasing the scale, scope and interactions of challenges faced by children and their families, communities and service providers. The result is historically unprecedented numbers of children and young adults requiring palliative care, and of children living with someone who is in need of palliative care. Palliative care practitioners need to affirm and build on existing caring resources present in every person, household, family and community. External support can strengthen or undermine the resilience and social and material resources. The approach that is taken in any intervention is key to its long-term success or failure.

Gender issues In children

The rights of all children in South Africa are protected by the Constitution of South Africa, the Children's Act, and various national and international Charters such as the UN Convention on the Rights of the Child (1989). However cultural and social factors may affect the right to gender equality both in the way society perceives the roles of girls and boys; and in the expectations related to the provision of care and support in households where the parent/primary caregiver may be absent, sick or elderly.

The burden of caring for themselves and their siblings, in

these households, often falls on the girl child, who then sacrifices her right to education, right to play and right to protection, when carrying out this role.

Government, hospice palliative care programmes and services for children should protect the rights of each child, whether female or male; be able to identify, intervene and report cases of child neglect, abuse and exploitation, and be aware that girls are more vulnerable in these situations.

Primary Caregivers of children are usually female and also may be single, and/or elderly, and living in poverty. These factors may prevent their ability to promote gender equality in communities where culturally and socially the male child is seen as more important than the girl child. Male children often grow up without a male role-model or father-figure which may affect their view of gender.

When the parent/primary caregiver dies, palliative care programmes may need to intervene to protect discriminatory inheritance rights of the widow and the female child in personal laws and customary practices. Gender issues need to be considered in providing children with access to sexual and reproductive information, including family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted infections (STIs) and must take into consideration changing cultural views about children's need for contraception and STI prevention and addressing cultural and other taboos surrounding adolescent sexuality and sexual orientation.

Paediatric Palliative Care in practice

There are new opportunities to ensure that children needing palliative care actually receive it. The National Strategic Plan for HIV and AIDS, and STIs 2007–2011 has paediatric palliative care targets. South African National AIDS Council (SANAC) is responsible for a mid-term review and in the next period there will be opportunity to further strengthen this provision. For ongoing issues related to this, there are structures within the South African National AIDS Council tasked with monitoring and supporting implementation. They can be approached with issues that require attention.

Children as partners in their own care

Effective paediatric palliative care depends upon a multiplicity of partnerships, but most importantly with the child. Building partnerships with children in their own care is vital and too often neglected. When only parents are

consulted, important and insightful perspectives of the affected children are missed that could improve care quality. When children are partners in their palliative care, they are:

- Happier
- Feel included and cared for
- Healthier
- Take on appropriate responsibilities
- Talk about their hopes and worries
- Cope better
- Know what to do and what not to do
- Share in their palliative and health care

Children who are partners in their own health care know the basic facts about their illnesses or condition. They have important information that has been communicated in appropriate ways. They know what treatment and care they should have and how important it is. They have the skills to put their knowledge into practice – for example the skills of washing hands thoroughly. They are involved in decisions about their health care, and are listened to and respected.

Co-operation is built on trust. Children must believe that the adult carers have their best interests at heart. They need to trust that carers will provide ongoing and consistent care and protection.

Trust depends also on honesty. While children should never be told a lie – they do not need to be told the whole truth. What they are told, needs to be as much as they will understand and what they can cope with at that time. But whatever they are told it must be the truth, because if they find out that a person has lied to them, they will feel betrayed and will no longer trust that person.

‘Disclosure to a child is a process, not an event’, is the most often repeated advice provided on disclosure to children. Who decides to tell what, how and when are decisions that the primary caregiver should make with the health care worker. Palliative care providers need to be included in this process.

The Children’s Act 38 of 2005 Section 10 provides a legal obligation to ensure Child Participation and states:

Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

Consent and assent

Children should be offered real choices about their care and treatment where possible and reasonable. For children under 12 years, decisions on treatment rest finally with the parent or guardian and the health-care worker. There are certain choices which adults need to make for the child, according to the child’s best interests. If an adult is going to decide, then the child should not be offered the illusion of choice. Palliative care workers can assist primary caregivers to find real choices appropriate to the child. This can be as simple as: ‘You can eat now or in 15 minutes.’

But it is better if a child AGREES to the treatment or care – gives *assent*. Then he or she is less anxious and more resilient, even if there has to be a painful procedure.

This assent and co-operation depends on children understanding and accepting their need for health-care and is a major part of their participation in health care. They need to know the facts and to accept them – to assimilate them into their lives and to put them into practice as far as they can. If there is medication to be taken, this is explained to the child in words he or she can understand.

The Children’s Act No. 38 of 2005 provides the legal framework for consent in relation to medical treatment and surgical procedures. Specific provisions include conditions under which a child may consent to his or her own medical treatment. The criteria include the child’s age *plus* their maturity and capacity.

Specific health problems

The most critical childhood illness in South Africa is HIV/AIDS. HIV/AIDS accounts for 40 per cent of deaths in children under five years, but it could be eliminated with improved prevention in adults and effective Prevention of Mother To Child Transmission (PMTCT). Children with HIV/AIDS get sick more quickly than adults do, and the illness progresses more rapidly without treatment. Co-trimoxazole prophylaxis and Highly Active Anti Retroviral Therapy (HAART) are two critical interventions in which palliative care workers could play a role in reducing suffering, disability and death. Children respond well and can adhere to HAART. Children Living with HIV/AIDS who are not on HAART are at high risk of having both physical and cognitive developmental challenges. Once on HAART, these risks drop dramatically. Early detection and treatment of HIV/AIDS in children – with special attention to developmental monitoring, early intervention and support – should be high priorities. Palliative care workers are ideally placed to turn this epidemic around, and consequently reduce their own workload.

Pain and symptom management

Pain and symptom management are essential elements of palliative care. The effectiveness of pain interventions depends on the availability of palliative care drugs and analgesics (including morphine), access to these medications, and health professionals trained and skilled in pain and symptom management. Pain is a common experience in children, however it is often overlooked or ranked low in care priorities.

Minimising or eliminating pain and suffering in children has a positive effect on everyone, including other children in the household and the caregiver. However, the assessment of pain in babies and even in older children can be difficult when they cannot describe their pain, and different skills and tools are required and available. Pain assessment tools must also take into account cultural differences and factors that influence interpretation of the tool. Education and training in paediatric palliative care is scarce and not available in South Africa, except for short, introductory courses. Health practitioners are afraid of prescribing morphine for children and children are left in pain rather than having effective analgesia administered.

What do children say about what hurts? One study reported pain and discomfort as the factors most frequently cited by children as the worst aspects of hospitalisation and the areas most needing improvement. Children said that play activities helped and were valued by children of all ages. Unfortunately, the value of play, both as a right and as distractive therapy, is seldom recognised even though children may continue to play until the day of their death.

In order to hear children's views and experiences, regular opportunities for seeking their unique perspectives should be included in ongoing programmes of quality assessment.

In addition to physically obvious pain, children can experience pain that is:

- Social – being ignored, excluded, discounted, unloved, treated unfairly or badly
- Psychological – fear, anxiety, horror
- Spiritual – humourless, hopeless and without future or possibility of relief, loss of joy, wonder and awe.

Links to other parts of the child's life

Palliative care for children needs to be integrated into other parts of a child's life. For example, basic child health care needs to be provided such as immunisations (unless contra-indicated) and growth monitoring. Care for a child receiving palliative care may need to be co-ordinated

with the guidelines on the Integrated Management of Childhood Illness. Children may benefit from attending Early Childhood Development programmes and ordinary schooling with other children, or those who are too frail and need protection may need to have these rights fulfilled by having services provided at home. The principle of a child's best interest guides these difficult decisions, balancing a child's rights to socialise, to education, to inclusion and to health care. Some children may be able to attend school most of the time, but may have multiple or extended periods of absence. Palliative care workers will need to work with other service providers to ensure that a child's right to education is not violated.

Child development: Ages and Stages

As children grow and develop, they pass through many stages, each of which is characterised by windows of opportunity, different capacities and inclinations. These are seen in typical changes – physical abilities; behaviours; ways of communicating, relating; problem-solving; and risk-taking. Children at different stages differ in **what they can and need to do**, as well as in **what care and protection they require**. These developmental phases are commonly called 'Ages & Stages' because developmental phases roughly correspond to age ranges. But ages are only a guideline.

Some important points to note are:

- Girls and boys have the same developmental needs.
- The **quality** of childcare is critically important for a child's development. A sensitive-responsive caregiver is one who sees the world from the child's point of view and seeks to meet the child's needs rather than just serving their own. Thus supporting a child's primary caregiver is a critical component of palliative care. This may mean identifying depression or social problems and seeking to link the adult to appropriate services.
- **'Attachments** are the emotional bonds that infants develop with their parents and other key caregivers. These relationships **are crucial for children's well-being and for their emotional and social development**. Attachment is an organising core in development that is always integrated with later experience and never lost.'

Training in palliative care for children will need to include childhood development and assessment and understanding of the different ages and developmental stages of childhood including adolescence. This training also needs to include recognition of possible developmental delays, and information on how to refer and to whom referrals can be made. For example, young children living with HIV/AIDS

who are not on HAART are at high risk of having both physical and cognitive developmental challenges. Once on HAART, these risks drop dramatically. Special attention to developmental monitoring, early intervention and support should be high priorities.

Legal tools

The Children's Act (**Act No. 38 of 2005**) and Children's Amendment Act will play a strong role in guiding future policy and practice in paediatric palliative care as there are specific sections on children with chronic illnesses and those with disabilities. The Act:

- changes the age of majority to 18 (effective 1 July 2007);
- changes the minimum age of consent for specified matters to 12 years old, but combines this with an assessment of maturity and capacity;
- These specified matters include consent to medical treatment, surgical operations, access to contraception, HIV testing and disclosure of results;
- Extends the basis for determining the child's ability to consent from age alone, to now including an obligation to make an assessment of the child's maturity and ability to understand the risks and benefits of any treatment or testing;
- Obligates government to ensure appropriate support and special services for children with disabilities and chronic illnesses.

There is specific reference to children with disabilities or with chronic illness in relation to the standard of 'Best interests of the child' in Section 7.

(1) Whenever a provision of this Act requires the best interests of the child standard to be applied, the following factors must be taken into consideration where relevant, namely:

- (i) any disability that a child may have;*
- (j) any chronic illness from which a child may suffer;*

In addition, Section 11 deals specifically with children with disability or chronic illness.

- (1) In any matter concerning a child with a disability, due consideration must be given to:*
 - (a) providing the child with parental care, family care or special care as and when appropriate;*
 - (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;*
 - (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and*
 - (d) providing the child and the child's care-giver with the necessary support services.*
- (2) In any matter concerning a child with chronic illness due consideration must be given to:*
 - (a) providing the child with parental care, family care or special care as and when appropriate;*
 - (b) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community; and*
 - (c) providing the child with the necessary support services.*
- (3) A child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, well-being or dignity.*

The Children's Act contains provisions for a National Child Protection Register which records reports, convictions and court findings of children in need of care and protection as a result of child abuse and deliberate neglect. In all such instances the register must reflect on whether the child has a disability and/or chronic illness and if so the nature of the disability or chronic illness.

Children in hospice Palliative Care programmes – From rights to wrongs and back again

CASE STUDY – BENNY

Benny was three years old when referred to a hospice programme by a hospital. He was an orphan cared for by his maternal grandmother who was employed as a domestic worker, and living in a shack in an informal settlement area. Admitted to a children's in-patient unit with HIV-related disease, severe malnutrition, hearing loss from frequent and untreated ear infections, unable to speak or to eat solid food, he was also severely developmentally delayed.

Grandmother did not visit the child, despite frequent attempts by the hospice community nurse to get her to do so. She continued to receive the foster care grant. Benny stayed in the in-patient unit for 15 months and developed a strong relationship with a hospice volunteer who was able to get the child to eat solid foods and obey simple instructions, and who expressed a desire to foster Benny. The volunteer also bought all Benny's clothes and toys and took him out for a day each week.

Despite her offer to foster him, the Department of Social Development felt it was in the best interest of the child for him to be returned to the grandmother. The hospice insisted that the grandmother receive training in giving ART before the placement and expressed their concern, both verbally and in writing, to the Director that Benny would again be neglected by his grandmother.

On follow-up of Benny, it was found that his grandmother had left him alone in the shack, had not taken him for his follow-up visit to the ART clinic, and had not been giving Benny his ARVs. This was immediately reported to the Department of Social Development who have been slow to respond. The hospice and the volunteer have made frequent visits to Benny to ensure that he has clothes and food as well as a bed to sleep on and have taken the child for ART follow-up. The hospice continues to report to the Department of Social Development, but does not wish to bring the case to the attention of the media or human rights lawyers as they are dependent on their relationship with the Department.

Protecting children's rights to family care

Hospices are often ideally placed to raise awareness of the needs of children they care for. However, as they have no legal standing to remove children or to place them in foster care, they are dependent on the actions of government services or other authorised organisations such as Child and Family Welfare agencies, who are often themselves dealing with a huge backlog of cases. Once children are placed in in-patient units for holistic care and nutritional therapy, they often improve dramatically, leaving the hospice as physically healthy children without suitable care in the community. Decisions concerning who has guardianship also place hospices in a vulnerable position when acquiring consent for admission to hospice programmes and treatment. This has led to children's in-patient units also registering as Places of Safety or shelters, but does mean that these hospices are carrying out a responsibility other than palliative care.

Children in households headed by vulnerable people

Children with life-limiting conditions often live in households where the primary caregiver is her/himself also vulnerable. Hospices are required to assist in accessing support for children, elderly relatives or sick parents who may be unable to access social support either through lack of knowledge, lack of finances or their own age or health status. Children heading households may not be able to complete their own schooling as they need to find resources to assist them to care for the family, or may need to be at home to care for babies and very young children or sick parents. The children and elderly heading households may also lack the knowledge and skills to provide safe and effective care. Hospices need to provide training, and access special resources for them, such as cots and baby feeds; as well as available social grants.

CASE STUDY – LIZZIE

Lizzie is a bright and happy 8-year-old girl with a chronic, genetic heart condition. As she is an orphan, she stays in a child-headed household with her older siblings (14 and 17) who are very caring, feed and clothe her well, and make sure she attends clinic appointments and that she takes her medication properly. They live in a small house that belonged to their mother, who did not leave a will. The 17-year-old boy does gardening on Saturdays to generate extra income and the 14-year-old girl sees to all the housework and cooking, often missing school to carry out these activities. Due to her condition, Lizzie requires frequent hospitalisation or admission to a hospice in-patient unit which disrupts her schooling, and this has meant that she started school late and has had to repeat Grade one. The school also complains when Lizzie's siblings cannot pay school fees for her or themselves. When her siblings are writing exams, they find having Lizzie at home makes it difficult for them to study properly, and request the hospice to admit her over these periods, which further disrupts her schooling. Her grandmother has now asked for guardianship of Lizzie, but not of the other siblings, as she does not want the responsibility of adolescents. The mother's family also claim that the house in which the children live belongs to them. Lizzie and her siblings would rather stay together in their mother's house with support from the hospice.

Right to education

No child may be denied education on the basis of being unable to pay school fees. Any child living in a child-headed household is exempt from paying school fees. Children who are forced by circumstances to live in child-headed households will need support in ensuring that this right is realised. School fee exemptions must be offered by the school, and the school must assist those requiring such exemptions to apply for them. A child with a chronic condition must be supported by the school so that during any absence, arrangements are made for her to receive any work that she may be missing. The hospice needs to play an active role in ensuring this continuity of education.

Right to inheritance

South African law provides some protection for children's inheritance in a situation in which someone has not left a will. However in practice this law is not protecting all children. A combination of factors dispossess children: lack of awareness of children's rights, complexities and the cost of the legal and court requirements, and sometimes conflict of interest of relatives as legal guardians who may feel entitled to the property. Traditional protection for children's inheritance was by practices that reinforced the acceptance of orphaned children by their father's family, but these practices no longer function. Customary and formal law are in conflict. Case law exists which has resulted in a review of customary law on succession.

Palliative care workers can approach the South African National AIDS Council through its Programme

Implementation's Technical Task Team on Human Rights and Access to Justice which has responsibility for monitoring and addressing implementation of the National Strategic Plan on HIV and AIDS and STIs 2007–2011, which has, under Objective 19.4: 'Ensure laws, policies and customs do not discriminate against women and children' and the Intervention: 'Develop and implement guidelines on the impact of HIV on the Master's Office and running of deceased's estates, with focus on women and children.'

Psycho-social care of children and adolescents facing life-limiting illness and death

Children and adolescents within hospice palliative care programmes face loss and death – either their own or that of a family member – or often both. Hospice programmes prepare children and parents for death through activities that promote resilience, such as holding family conferences to plan for the safe care of children once the parent dies; memory approaches such as developing a Memory Box with special items left for the child; Memory books where parents record their family history, family stories and dreams for the child; and Hero books where the child becomes the hero of their own story. Psycho-social and developmental support is provided through one-to-one counselling; support groups, holiday activities and day-care and after school care centres.

A major challenge for hospices is either a lack of social workers in their district or a very high turnover of staff providing psycho-social services who can obtain better

CASE STUDY – CINDY

Cindy is 12 years old and lives with her mother, 15-year-old brother Thomas, and 17-year-old brother Neo who has muscular dystrophy. Her mother has a job and cannot care for Neo who requires full-time care as he is in a wheelchair and cannot feed himself. The children's granny helps when she is not working, but Cindy has to stay away from school to care for Neo at least twice a week and has fallen behind with her schoolwork. She is also frightened that something will happen to Neo when she is alone with him; and gets angry that she cannot spend time with her friends.

salaries and benefits in the formal health and welfare sector. This results in limited bereavement and emotional support for children at a critical time of their lives.

Who cares and at what cost? The burden of caring for sick family members often falls on girls, affecting their access to a good education, denying them time to play and relax, to socialise, and limiting opportunities for employment when they are older. A few Hospices have day-care centres from Monday to Friday but these are usually for pre-school children. There are few facilities for adolescents with life-limiting conditions requiring full-time care.

Promoting children's right to play in Palliative Care

All children have the right to play, every day. It is a basic need of human development and well-being as vital as food, water and rest. It is essential for quality of life. It improves health – both mind and body. Play is children's way of engaging with and making sense of the world around and within themselves. Through play children develop competencies, self-perceptions, social skills and relationships. It is a key to learning life lessons about respect, inclusion, leadership, co-operation and more.

If a child is not playing – check for pain or other problems. Children with life-limiting illness often experience pain, sadness and suffering for short and intense periods. They are often easily distracted by play, music, storytelling and art. Children's palliative care services need to recognise this and integrate these activities into holistic care programmes, including supporting play in the home. Where programmes focus on clinical interventions only, the child's right to play may be compromised.

Protection of children

Child Protection includes protection from abuse, neglect and exploitation, Abuse may include physical,

emotional, intellectual, social, and/or sexual harm.

Neglect may be deliberate or as a consequence of the ill-health or mental state (such as depression) of a caregiver. Palliative care workers can provide protection in such situations as they can identify and report abuse, neglect and exploitation, as well as support the development of resilience in children through simple interventions, and promote a safe environment. They can raise the awareness of caregivers to minimise avoidable dangers, and to develop children's life skills. Palliative care programmes should include ongoing education on recognising and dealing with abuse. Palliative care workers can strengthen their relationships with child protection workers to improve referrals and support.

Rights for children of refugees and asylum seekers

Not all children in South Africa are South African, however there is a duty to fulfil their human rights, including health care. This has relevance for palliative care provision. A National Department of Health Directive has confirmed the right of refugees and asylum seekers and their children, with or without a permit, to access basic health care and ART on the same basis as South African citizens.

A draft paper by Sharon Pillay, an attorney at Pro Bono.Org, outlines that in February 2007 the United Nations High Commission for Refugees (UNHCR) issued *Guidelines on Policies and Procedures in dealing with Unaccompanied Children Seeking Asylum*. The UNHCR Guidelines states that 'The basic guiding principle in any child care and protection action is the principle of the 'best interests of the child'.

Unaccompanied minors are vulnerable and marginalised and lack the necessary protection and security. They require immediate protection and assistance. Accordingly they will almost always be in need of care and protection.

SA Law relating to foreign unaccompanied minors

Presently, unaccompanied foreign minors are dealt with under the Child Care Act. Section 32 of the Refugees Act 130 of 1998 provides that any child who appears to have a refugee claim and is found to be in need of care as contemplated in the Child Care Act must be brought before the Children's Court which may make an order that the child concerned be assisted in applying for asylum. The Children's Court will make an order providing protection, care and financial assistance through a placement in a foster or children's home which has been approved by the state.

Once the Children's Act comes into operation, unaccompanied minors will be dealt with under Section 150. If it appears that a child who is resident within the jurisdiction of the presiding officer, he or she must designate a social worker to complete an investigation into whether the child is in need of care and protection as contemplated in Section 155(2). The presiding officer can at the same time order that the child be placed in temporary safe care.

In giving effect to South Africa's obligations both nationally and internationally, the 'best interests of the child' principle must be applied as soon as it is ascertained that the child is unaccompanied and should maintain its uniformity throughout the asylum process.

Recent case law regarding foreign children

In *Centre for Child Law vs Minister of Home Affairs*, the rights of unaccompanied foreign children who were detained in South Africa came under scrutiny. The Court held that:

- All unaccompanied foreign children found in need of care should be dealt with in accordance with the provisions of the Child Care Act, which includes asylum seekers and refugee children.
- They must be brought before a Children's Court for an enquiry into their circumstances to be conducted when they are found to be in need of care.
- If it appears at the enquiry that a child has a refugee claim, that child should be assisted to submit an asylum claim in accordance with Section 32 of the Refugees Act.
- The South African government is directly responsible to provide for the socio-economic and educational needs of unaccompanied foreign children in South Africa.
- Unaccompanied foreign children may no longer be detained at the Lindela Repatriation Centre. They must be provided with legal representation at the State's expense.

Things to remember

- Palliative care for children including adolescents may be provided over many years and includes a wide range of conditions often not found in adults.
- Practitioners require special knowledge and skills to care for children of all ages including adolescents.
- A children's rights approach underlies effective paediatric palliative care programming.
- Meaningful applications of children's rights must be based on an understanding of child development that addresses the realities of each unique child.
- Children should be involved as partners in their own palliative care.
- Decisions made for and with children must be in their best interests, where they are not, they must be challenged.
- Life-limiting conditions increase the vulnerability of children.
- Children require psycho-social support but this does not always mean specialist services are required. It is essential to develop children's resilience and strengthen the psycho-social environment and skills of those closest to the children and their families.
- Palliative care providers face many challenges that require training, expanded response and advocacy.
- Children and their caregivers need more information and support in accessing their right to health and social support, including birth registration, education, grants, social and psychological services.

What you can do

- Recognise and relieve pain, discomfort and suffering in children of all ages.
- Eliminate paediatric HIV.
- Ensure early diagnosis and treatment of children for disabilities, and chronic, life-limiting illnesses and conditions .
- Identify children at risk of harm and in need of protection from violence, abuse, neglect, exploitation, poverty, stigma.
- Learn about, use, monitor and support existing legislation and plans such as the NSP.
- Participate in co-ordinating structures such as SANAC and Provincial Advisory Councils on Children.

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