

Children's Palliative Care in South Africa

The Facts



“Children’s palliative care cannot claim to protect the **quantity** of a child’s life. But children’s palliative care can claim to protect the **quality** of a child’s life, and of course to relieve suffering. There can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible.”

Justin Amery, MD

Acknowledgements

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Foreword

Palliative care for children and young people has many similarities to palliative care for adults – but also has many differences. Those caring for children with life-limiting or life-threatening conditions may see children with diagnoses that are never seen in adults, and may be called on to care for tiny neonates with only a few hours, days or weeks to live.

For many people, the thought of children suffering or dying is something that cannot be imagined or faced. The reality is however, that many children in South Africa and in the rest of the world do suffer and die from a wide variety of conditions, including severe malnutrition. Those caring for them need an understanding of palliative care and the issues specific to palliative care for children.

This Fact Book is for anyone who wishes to know more about palliative care for children; and for care professionals who may be interested in developing knowledge and skills to care for the neonates, children and young people whose vulnerability calls for both knowledge and skill to relieve their suffering, respond to their needs, and improve the quality of their lives, and of their dying.

Joan Marston

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Why Children's Palliative Care?

In recent years the developed and developing world has seen an increase in the prevalence of incurable disease and disability. In South Africa the high incidence of HIV/AIDS has shifted the focus from paediatric palliative care patients with cancer, metabolic disorders, neuromuscular disorders, organ failure and other severe conditions to address the complexities around HIV/AIDS. The time has come to broaden our reach and to provide palliative care to *all* South African children living with a life-limiting or life-threatening illness.

Nelson Mandela has said that 'there can be no keener revelation of a society's soul than the way in which it treats its children'. For many years palliative care was not offered to paediatric patients and even today only a minority of children with incurable illness benefit from palliative care services.

Too many South African children requiring paediatric palliative care die in inadequate conditions, without adequate relief from distressing symptoms. The children usually die in hospital settings and rarely in their own home with the care and support of their family.

- In rural African communities, 94 out of every 1000 children under the age of one year will die.
- 115-138 out of every 1000 South African children under the age of five years will die
- 81% of child deaths in South Africa were children under 5 years
- 35% of children under 5 years die from HIV/AIDS related conditions
- Neonatal deaths account for 30% of deaths
- Malnutrition is a key contributing factor to child mortality in South Africa: 60% of children under 5 who died in hospital between 2005 and 2007 were underweight

South Africa is one of only 12 countries that are not on track to reach the Millennium Development Goals (MDG) to reduce under 5 mortality

Palliative Care for Children requires skills, organisation and resources which are unique and specific to children.

'Matters of life and death are too hard, too onerous, too painful to do alone'
Kaethe Weingarten

What is Children's Palliative Care?

The term "Palliative care" is derived from the Latin *palliare*, [to cloak] and refers to an approach to medical care which is focused on reducing the severity of distressing symptoms rather than striving to cure, halt or reverse the progression of a disease. The goal of palliative care is to prevent and relieve suffering of any kind and to improve quality of life for people faced with serious and complex medical conditions. Palliative care is not dependent on prognosis and is offered alongside curative and all other appropriate forms of treatment. Palliative care addresses total pain, which includes pain of the body, mind and spirit.

Palliative care for children is a response to the suffering and unique needs of each child with a life-limiting or life-threatening condition. It is a holistic, professional and active approach to caring that includes pain and symptom management. It is applicable from the peri-natal and neo-natal period until the child either dies or becomes a young adult.

The **World Health Organization** (WHO) defines palliative care for children as a special, albeit closely related field to adult palliative care which includes:

- The active, total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's [own] homes.

Childhood is considered to begin from the peri-natal and neonatal period until 18 years of age. However, if the young adult is still at school and dependent, they could be considered a child under the South African Child Care Act.

A **life-limiting** illness is a condition where premature death in childhood or early adulthood is usual, but not necessarily imminent.

A **life-threatening** illness is a condition where there is a high probability of premature death but there is also a chance of long-term survival to adulthood. It should be stressed that not every child with a life-threatening condition needs continuous care by palliative care specialists throughout the course of the illness. Once the immediate threat to life has receded, if possible the child should be exited from a palliative care programme to appropriate supportive care.

Terminal care is also referred to as **end-of-life care** and refers to the care of the patient and family limited to the period when curative treatment has been suspended and death is imminent.

Conditions eligible for children's palliative care

Over 360 conditions have been identified as eligible for the provision of palliative care to children. In South Africa, based on the four categories recognised by the Association for Children's Palliative Care in the UK (ACT) the Hospice Palliative Care Association of South Africa (HPCA) recognises the following six categories as being applicable to its provision in this country.

ACT Category 1

Life-threatening conditions for which curative treatment may be feasible, but can fail e.g. cancer, organ failure of heart, liver or kidney, infections such as malaria and TB.

ACT Category 2

Conditions requiring long periods of intensive treatment aimed at prolonging life, but where premature death is still possible e.g. Cystic Fibrosis, HIV/AIDS failing ARV therapy/stage IV, epidermolysis bullosa, cardiovascular anomalies and extreme prematurity (newborn infants), severe renal conditions, severe respiratory diseases (non TB), Muscular Dystrophy.

ACT Category 3

Progressive conditions without curative options, where treatment is palliative after diagnosis e.g. neuromuscular or neurodegenerative disorders, progressive metabolic disorders, chromosomal abnormalities, advanced metastatic cancer, complex or severe cardiac disease, multiple congenital abnormalities where therapy has little to offer.

ACT Category 4

Irreversible, non-progressive conditions with severe disability causing extreme vulnerability to health complications e.g. severe Cerebral Palsy with recurrent infection, genetic disorders, congenital malformations, prematurity with significant neurological complications, severe CNS sequelae of infectious diseases, acute severe meningitis, severe spinal cord injury and severe hypoxic brain injury.

Category 5

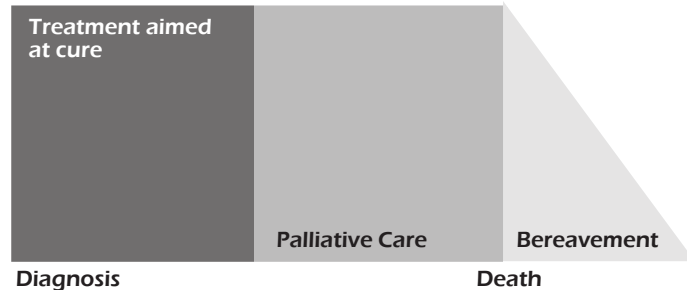
Bereaved children and children facing grief and loss

Category 6

Other children who require supportive rather than palliative care such as HIV affected children and children whose parent or parents have died and require ongoing holistic support and future planning. *These children should be referred to other support organisations once they no longer have a need for palliative interventions.*

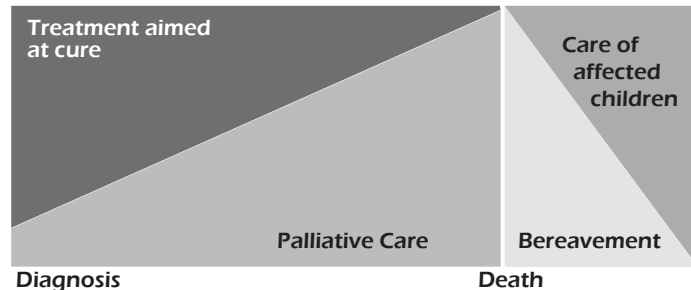
Palliative care service models

Traditional palliative care services model



The traditional palliative care model proposed that there was a “palliative switch point” at which aggressive interventions ceased and palliative treatments began.

Modern integrated palliative care services model



In the integrated model palliative care is applicable from the time of diagnosis and occurs alongside attempts at cure. As the disease progresses the amount of palliative care required may increase until a point is reached where the side effects of aggressive treatments may outweigh the benefits and care becomes exclusively palliative. The family is supported through the terminal stage and offered care and support during bereavement. Care does not end with the death of the child.

KEY POINTS IN CHILDREN’S PALLIATIVE CARE

- It provides comfort in the form of pain relief and the management of unpleasant symptoms
- It relieves suffering and addresses the needs of the child and family
- It requires an interdisciplinary team who have specific skills and experience
- It can run concurrently with curative treatment
- It is applicable from diagnosis and continues into bereavement
- It provides supportive, physical, psycho-social and spiritual care which includes members of the patient’s family

In the context of South Africa, palliative care is often more significant from the time of diagnosis due to late presentation or lack of resources and options for curative treatment. Bereavement care is also complicated when the death of a parent (usually from an AIDS related illness) leaves behind orphaned and vulnerable children who may or may not be infected. The hospice service will then support and care for these children for as long as is needed, or until they are able to be placed under the care of appropriate services within the community.

Disease trajectories

A disease trajectory is a graphic representation of health status over time and understanding them can assist with decision making. These trajectories represent the relationship between palliative care and treatments aimed at cure or prolonging life.



As the illness progresses the emphasis gradually shifts from curative to palliative treatment.



Aggressive treatments may be used to prolong life and improve quality alongside palliative care, each becoming dominant at different times.



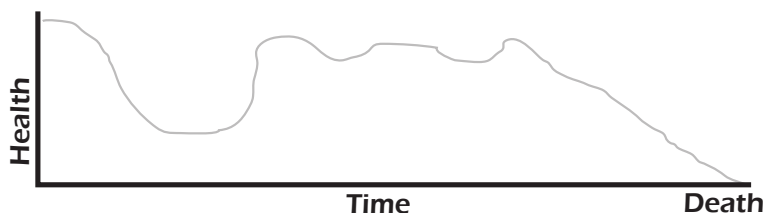
No cure is possible and care is palliative from the moment of diagnosis.



Initially it is not apparent that this will be a terminal illness and palliative care starts suddenly once this becomes obvious.

 Curative  Palliative

Trajectory of an ACT Category 2 Illness



In this alternative graphic representation of the trajectory of an illness, the level of health deteriorates until a diagnosis is made and returns to an acceptable level and maintained by treatment until treatment fails or needs to be withdrawn.

KEY POINTS

- The conditions eligible for palliative care for children are multiple and wide-ranging
- The duration of care is variable and difficult to predict
- Palliative care does not exclude curative treatment

Levels of palliative care

The level of palliative care interventions offered to children will depend on the diagnosis, prognosis, access and adherence to medication and support systems in place for the child. The child's palliative care plan is adapted to the particular needs and circumstances of the child.

These levels can be described as follows:

Primary level of Care

Aimed at children with less severe conditions or less severe symptoms where control of symptoms and on-going support is practiced by all healthcare workers as part of an interdisciplinary team. The children's palliative care team could act as consultants or in a supervisory position. Networking and using of all available community resources will expand the quality of care.

Secondary level of care

Care is aimed at children with complex needs requiring a number of interventions that include interventions from a hospital and community clinics who are not exclusively involved with children's palliative care services but who have specific skills. The primary care facility could be an institution that engages the services of the children's palliative interdisciplinary team.

Specialised level of care

This is care aimed at complex conditions that necessitate continuous care of professionals working exclusively in the children's palliative care sector who are members of an interdisciplinary palliative care team. The team could either be based at a palliative care hospice or be in a hospital setting.



Remarkably, these pictures are of the same child, before and after palliative care intervention. The level of care given on first presentation was specialised as her condition was life-threatening. Since regaining her health, she has returned to her family and has need for palliative care interventions at the primary level.

Complexities of children's palliative care

Small numbers of patients with conditions other than HIV/AIDS has resulted in a lack of experience, knowledge and confidence in managing palliative care for children.

The **broad range of conditions** affecting children need a wide range of experience and consultation.

Limited availability, knowledge and use of **drugs for children** impacts negatively on effective symptom management.

Child developmental factors influence dosages, communication, knowledge and support.

Family and community attitudes impact on the clinical, ethical, social and spiritual care and decisions taken.

The **time scale of children's illnesses** is generally different from that of adults; palliative care may last only a few days or months, or may extend over many years.

Children's palliative care practices and technology is often not integrated into **rapidly advancing curative medicine** practices, which is prolonging the survival of children who until recently would have deteriorated rapidly or have died.

Emotional involvement when a child is dying affects family cohesion, sharing care, ethical considerations, staff over-involvement and burnout.

Grief and **bereavement** following the death of a child is often prolonged and complicated.

The legal parent or guardians' **cultural, spiritual, social norms and values** may complicate management. The child's legal rights, wishes and participation in choice-making may be in conflict with the wishes of the guardians.

The **social impact of a sick child in a home** may make it difficult for a family and the child to maintain their role with regard to school, work, income and friendships. The **provision of education** is an essential and legal entitlement for every child and introduces an additional professional intervention.

The **cultural and spiritual considerations** of the caring team and the family may inform care-giving in a way which prevents dealing with the complexities of symptom management and dying with dignity.

The holistic needs of children requiring palliative care

Children have complex palliative care needs determined by age, the course of illness, the family unit, the cultural environment, the spiritual awareness and information requirements which may require combined Health Care and community solutions.

Physical Needs

Symptom control: The timely pharmacological and non-pharmacological management of distressing symptoms by appropriately skilled professionals.

Pain management: Pain in children is often under-assessed and under-treated. The assessment of pain in children who are nonverbal, or do not understand the experience of pain, or are too young or disabled, malnourished or suffering from an infection like TB meningitis needs experience and knowledge of alternative methods of pain assessment. Pain is holistic and has physical, emotional, social, spiritual and cultural components. These aspects need to be identified and the 'voice of the child' needs to be included, if pain management is to be successful. Every child coming into contact with a health care centre will experience pain in some way or another. The World Health Organization is suggesting that low doses of morphine should be used when treating children with chronic pain. The ability to assess and treat a child's pain is part of the training of paediatric palliative care practitioners.

Growth & Development: The aim being for patients to reach their full potential through the provision of a stimulating environment and activities which promote the reaching of all developmental milestones.



Good pain management is a human right. 80% of terminal cancer patients and 50% of terminal AIDS patients require an average of 90 days pain treatment with morphine. In 2008, an estimated 59,000 children died of AIDS in South Africa, therefore 28,500 children would have required 90 days of pain treatment. HIV positive children are seldom assessed and given pain control. Why should children suffer?

Emotional Needs

Being diagnosed with a life-limiting illness has a significant emotional and psychological impact on the child. Their emotional needs include:

- Open, **clear communication** between the child and care providers which is appropriate to the developmental stage of the child
- Ongoing **emotional support** to assist the child to cope with emotive issues like understanding, acceptance, anger, rejection, stigma, self-confidence, trust and love
- Access to **resources and tools** to promote development of the child's personality, self-awareness, individual characteristics and talents as well as the attainment of their dreams and goals

Social Needs

- Identifying social activities offering appropriate opportunities for interaction with peers, groups and organisations
- Provision of schooling or school activities for as long and as often as possible
- Creating opportunities to play and to participate in appropriate recreational activities based on the child's age and individual preferences



Cultural Needs

- Creating opportunities for the family and child to inform caregivers about meaning-making cultural practices
- Together with the child and family discovering ways of being respectful to and operating within a cultural specific framework
- Using cultural consultants to guide interaction and cultural preferences with regard to treatment

Spiritual Needs

- Interactions with spiritual counsellors or chaplains with a knowledge and understanding of children
- Opportunities to participate in religious rituals and services relevant to the child's culture and beliefs as well as other activities that will contribute in a meaningful way to their quality of life.
- Assessing those aspects of care which could address improving or maintaining the quality of life of the child

Information Needs

- Information presented in such a way that it considers the age, language, progression of illness, culture, spirituality, development and education of the child
- Ethical guidelines must be employed when considering the information needs of the child and the expectations and fears of the family and caregivers

Palliative Care for children with HIV & AIDS

This disease cannot be seen in isolation from community and cultural needs.

Children with HIV/AIDS can live to adulthood and can lead normal productive lives if a way is found to ensure ARV adherence and the child is given hope for the future. HIV/AIDS has the potential to be a chronic illness like diabetes if it is approached in a holistic manner. It is the attitudes and knowledge of the hospice or hospital staff, the child, the family, the community and the school that will make the difference between the child **living positively** or dying.

This challenge to hospices has resulted in many of them becoming innovative with psychosocial, support programmes when dealing with children and communities infected and affected by HIV/AIDS

Palliative care programmes support children who are HIV positive in the following ways:

- Identification and diagnosis of children who are HIV positive
- Referral for ART, co-trimoxazole prophylaxis, TB screening and treatment
- Monitoring and support for drug adherence
- Early identification of drug side-effects
- Pain and symptom assessment and management
- Promotion of access to palliative care drugs including opioids, such as morphine
- Early identification and treatment of opportunistic infections and other illnesses
- Assessment of clinical nutritional status and nutritional support
- Psychosocial assessment and support to ensure the child's emotional and social needs are met
- Spiritual assessment and support of the child and family
- Bereavement support including memory work and help with anticipatory grief
- Sibling and family support
- Developmental assessments and support including early childhood development interventions, as 91% of children who are HIV positive have been shown to be developmentally delayed
- Support through transition from childhood to young adulthood and referral to adult programmes
- Care and support when the child is dying
- Bereavement support for the family

Needs of families facing the illness and death of a child

The family are those people who provide physical, psychological, spiritual and social comfort and nurturing to the child, regardless of genetic relationships. **The adult care-providers or parents** often become health care providers and take on the responsibility of administering treatments and having to make decisions which are in the best interest of the child at a time when they are overburdened and grieving the loss of a child's health. **Siblings** may suffer feelings of guilt, loneliness, neglect and may experience social isolation as well as sadness, grief and loss.

Families and siblings have complex needs which need to be assessed and managed adequately. These could include:

- A thorough knowledge and information about the child's condition
- Knowledge of how they can provide the best holistic care for their child
- Financial assistance or social support due to the burden of providing medication and treatment for the patient
- Appropriate emotional and bereavement support to all the family members, including grandparents and siblings
- Respect and space for their cultural, spiritual and religious practices

End of life Care

While palliative care is about giving the child the best quality of life, it is also there to ensure that when the time comes, the child's death is as "good" as it can possibly be. Palliative care professionals see a child's death as a natural event and they will do all they can to help the family and the child prepare for this event, while still respecting the spiritual, cultural and social norms of the family. This may be the most difficult part of the palliative care professional's work which is often hampered by poor attitudes and misconceptions - such as doctors who see the child's inevitable passing as a personal failure, and families who are in emotional denial.

The aim of care at the end of life is to ensure that the child has a 'good death'. Characteristics of a good death include:

- Adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Strengthening relationships with loved ones

Children and their families look for a peaceful, quick, pain-free death, in which they feel in control and without fear, with their families around them having said everything that needs to be said.



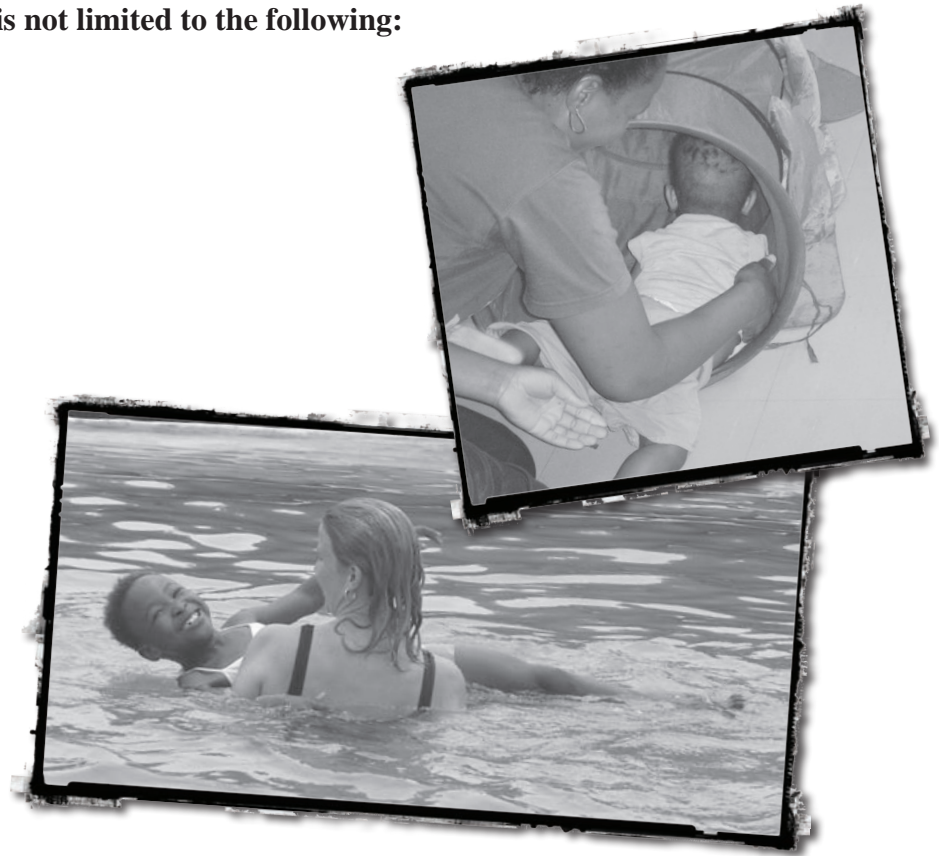
Responding to the needs

Palliative care for children is provided by an interdisciplinary team

The needs of life limited and life-threatened children and their families are multiple and complex and will be determined by their age, the course and stage of their illness, the family unit, their cultural environment and their spiritual awareness. These needs cannot be met by one person and always requires the intervention and the support of a committed **team of people**. All those drawn into the child's therapy and treatment will form part of his/her Care Team. All teams should also involve both the child and the family in varying ways and degrees.

Members of this care team could include, but is not limited to the following:

- Parents or Primary care givers
- Friends
- Community members
- Paediatrician
- Doctor
- Professional Nurse
- Staff Nurse
- Community Care Worker (CCW)
- Social Worker
- Social Auxiliary Worker
- Child and Youth Care Worker
- Chaplain or spiritual counsellor
- Educator / Teacher
- Early Childhood Development Worker
- Child life specialist
- Physiotherapist
- Occupational Therapist
- Speech Therapist
- Music therapist
- Art therapist



'Deep illness is a dangerous opportunity for sacred exchange between caregiver and patient.'

Arthur Frank

The interdisciplinary team

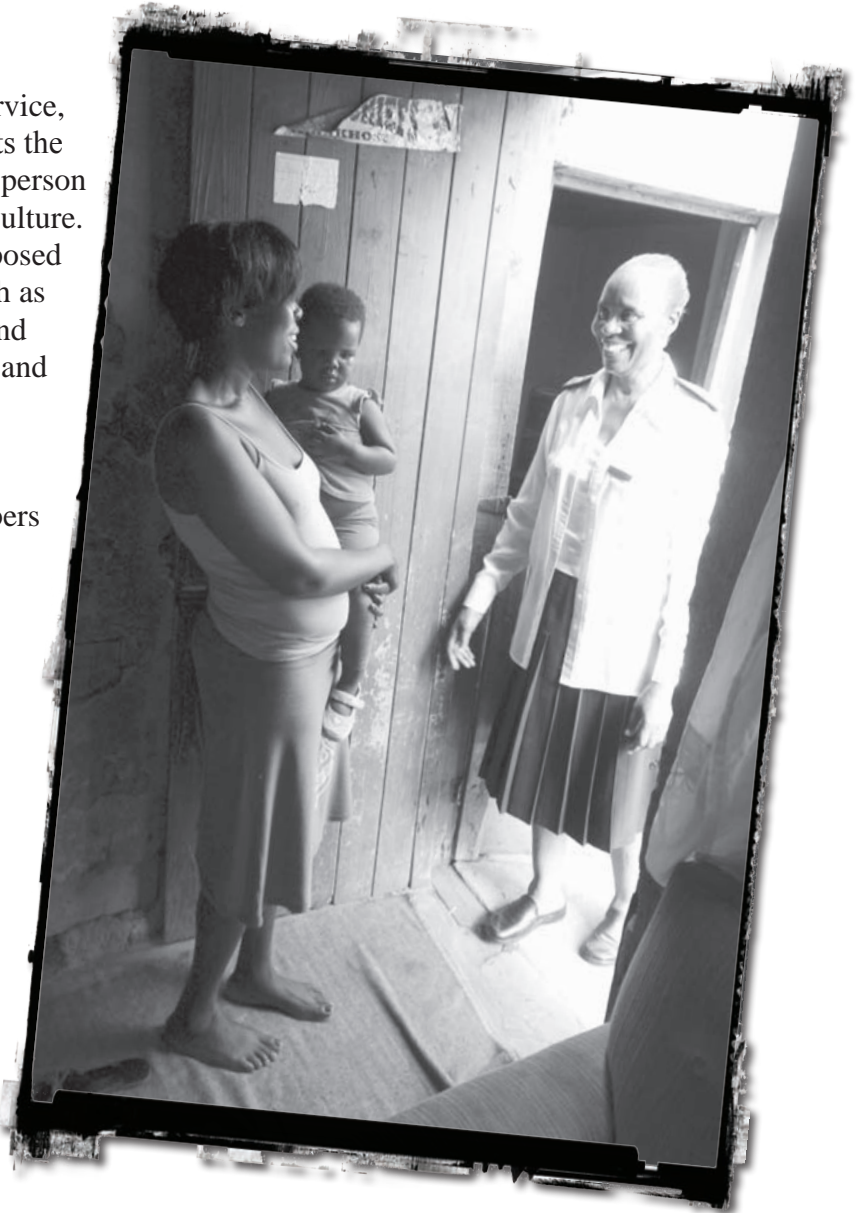
In order to provide a quality children's palliative care service, the **interdisciplinary approach** is preferable as it reflects the accepted view of a child as an integrated and interactive person seen within the context of their family, community and culture. Although different team models are used, most are composed of professionals representing a variety of disciplines such as social work, psychology, medicine, child development and physical, occupational and speech and language therapy and education.

Interdisciplinary teams are characterised by **formal channels of communication** that encourage team members to share their information and discuss individual results. Representatives of various professional disciplines may separately assess children and families, but the team does come together at some point to discuss the results of their individual assessment and to develop plans for intervention. Generally, each specialist is responsible for the part of the service plan related to his or her professional discipline.

The interdisciplinary team within the South African environment needs to find a way of including **the voice of the child and the family** while recognising the unique cultural and spiritual environment in which the child lives.

'The interdisciplinary team is like the composition of a symphony in which each instrument contributes a unique sound to the beauty of the whole.'

Duncan



In addressing the holistic approach to care, hospice palliative care programmes may include:

Physical Care

Home-visits, pain and symptom management, dressings, physical care, medical clinics, HIV testing and counselling, TB medication and ARV adherence, health and hygiene programmes, provision of equipment, food provision, delivering medication, supervising the keeping of appointments and referrals.

Social Care

Support groups, recreational activities, youth clubs, outings, provision of school uniforms, accessing of social grants, child protection issues, crafting and sporting activities.

Emotional Care

Support groups, individual counselling, family counselling, bereavement care, play therapy.

Spiritual Care

Individual counselling, networking with spiritual leaders.

Cultural Care

Games, dancing, music, drama clubs.

Educational Care

Home-work clubs, preschools, computer literacy, individual educational support, life skills

Care Plans

An interdisciplinary care plan is devised for each child, preferably together with the family and the child, by the interdisciplinary team. This care plan is monitored and reassessed at interdisciplinary team meetings and includes immediate, future and long-term plans as well as an end-of-life plan if indicated.



Models of children's palliative care in South Africa

Palliative care settings in South Africa are **tailored to the needs identified and the resources available in the area** in which the service is situated. To address the holistic nature of palliative care a number of organisations have expanded their programmes to include life skills, education, recreation, food provision and vocational skills when these resources are not available elsewhere. Networking and forming partnerships to share the responsibility and provide holistic care to patients adds to the quality of service provision.

Hospice based Children's In-Patient Units (CIPU)

This model is based on the first ever children's hospice (Helen House in Oxford, UK) where children are admitted for respite care, symptom management and end of life care. They require 24 hour staffing by professional nurses and active interventions by an inter-disciplinary team which includes medical doctors, social workers, psychologists, community care workers and other therapists. This is the most expensive model of palliative care provision.

Day Care Centres

This more cost effective model of palliative care provision can be based at a hospice or within the community. These centres may monitor and address medication adherence, symptom management, failure to thrive, malnutrition, neglect or abuse. These centres may include care for children *affected* by life limiting illnesses such as siblings of sick children and children who have been orphaned or made vulnerable by HIV/AIDS or cancer.

Drop-In Centres

This model of palliative care provision is a sanctuary where children can be provided with a nutritious meal, attend homework supervision, recreation activities, skills development, counselling and support groups. Symptom management and adherence to medication is monitored.

Hospital Based Care

This is where the hospital has a palliative care on-site team or they network together with a community palliative care hospice. This approach allows for the best of both worlds where an interdisciplinary palliative care approach within a hospital (hospice within a hospital) ensures appropriate active symptom management and a family-centred approach to the care plan. On discharge the palliative care hospice could continue care within the home and use the hospital for expertise and team support.

Community Home Based Care Programmes

Most hospice programmes offer community home based care services for children. This is the most cost effective model of care and includes care provision for the family and the community. There are very few times when this is not ideal, for example homes without electricity are not suitable if the child needs access to oxygen or other electrical equipment.

The advantages of family-centred home care are numerous and include:

- Diminished feelings of fear, isolation and helplessness
- Allowing the child to continue with family activities
- Offering important opportunities for communication and socialisation
- Allowing extended family to share in care responsibilities
- The home is familiar and more child friendly than a hospital environment



Comprehensive programmes with Hospital, Hospice, Day Care and Community Home Based Care Programmes

These programmes ensure a continuity of care for children from hospital to a hospice and/or Day Care Centre and the child's own home. They may be developed by one organisation or in partnership with several organisations.

Examples of this comprehensive model in South Africa include Sunflower House and the St Nicholas Bana Pele Network in Bloemfontein, The Bigshoes Foundation hospital programme and Soweto Hospice (In-patients and outreach) Cotlands in Johannesburg and Somerset West as well as the Butterfly House network model in Paarl in the Western Cape.



Legal and Ethical issues relevant to children's palliative care

Ethics is the study of the rational process for determining the best course of action in the face of conflicting choices and the moral principles of conduct that are considered correct by a profession or group. In children's palliative care, the study of ethics is imperative as it provides health care workers with the tools to approach difficult dilemmas in a more objective manner.

Ethical principles relative to children's palliative care include:

- Respect for life
- Autonomy - respect for the uniqueness of the individual and freedom in decision making
- Capacity - governs informed consent
- Beneficence - to do good
- Non-Maleficence - to avoid / minimise harm
- Justice - decisions need to be just and ensure a fair distribution of resources
- Truth telling - it is the duty of the practitioner to tell the truth at all times
- Confidentiality - the only exception being when there is a high risk of physical harm to others

Key dilemmas in the practice of children's palliative care

- The most important principles in medical ethics are those of autonomy and informed consent but children are often neither fully autonomous nor fully able to give consent.
- Health professionals may be as influenced (subconsciously) by prejudice and emotion as they (consciously) are by logic and rationality when it comes to decision-making in children's palliative care.
- Children have rights, and the duty of health professionals is to uphold and protect those rights as far as possible even when these conflict with the wishes of the family.
- Many of the ethical dilemmas in children's palliative care in South Africa are decided by the fact that the resources to carry out the ethical therapeutic options that are theoretically possible are not available.

The ICPCN Charter

We believe that **children's palliative care is a human right** and that every child, no matter their gender, age, race, religion, socio-economic background or geographic location has the right to experience the best quality of life possible and be allowed to die with dignity, surrounded by those they love in the place of their choice, free from pain and distressing symptoms.

These rights are summed up in the International Children's Palliative Care Network's **Charter of Rights for life-limited and life-threatened children** as follows:

1. Every child should expect individualised, culturally and age appropriate palliative care as defined by the World Health Organization (WHO) . The specific needs of adolescents and young people shall be addressed and planned for.
2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.
3. The child's parents or legal guardians shall be acknowledged as the primary care givers and recognised as full partners in all care and decisions involving their child.
4. Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.
5. A sensitive but honest approach will be the basis of all communication with the child and the child's family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.
6. Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.
7. The child and the family shall be given the opportunity to consult with a paediatric specialist with particular knowledge of the child's condition where possible, and shall remain under the care of a paediatrician or doctor with paediatric knowledge and experience.

8. The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.
9. The child's home shall remain the centre of care whenever possible. Treatment outside of this home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children.
10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.

Adapted from the ACT Charter
ICPCN 2008



The ICPCN Charter is available in other South African languages from the website: www.icpcn.org.uk

The status of Children's Palliative Care in SA

Since 2007, palliative care programmes for children in South Africa have increased from 6 to 58, mainly through the Paediatric Development programme of HPCA. The Bigshoes Foundation has spearheaded the development of paediatric palliative care in hospitals in 3 provinces.

Development has ensured that palliative care for children is available within hospices in all 9 provinces of South Africa. This rapid development has come about due to an innovative plan to integrate children's palliative care into existing hospice and palliative care organisations that were either predominantly adult-focused or providing supportive care to children.

The key elements of the development plan are:

- A situational analysis of the status of palliative care for children in Southern Africa
- Identification of hospices that were caring for children or who expressed an interest in developing a children's palliative care service
- Development of paediatric palliative care materials and a Toolkit for the implementation of children's palliative care
- Appointment of Paediatric Officers to provide ongoing support to hospices
- A Children's Palliative Care Programme Assessment Tool that is used to set a baseline and a Development Plan for each hospice
- The collaborative writing of a Textbook for Children's Palliative Care in Africa , edited by Dr Justin Amery
- The collaborative writing of a curriculum for a 6 month multi-professional Short Course in Children's Palliative Care, being piloted in Tanzania, Uganda and South Africa
- An HPCA Paediatric sub-committee (PAESCO) with representation from all provinces as well as from professionals with relevant expertise
- Advocacy that includes active membership of national children's forums such as NACCA and the Yezengeni Network
- Involvement in research projects related to children's palliative care
- Active membership of the International Children's Palliative Care Network (ICPCN) hosted by HPCA.



Challenges and recommendations for the future

Factors which hamper the provision of a quality palliative care service for the children in South Africa include:

- Limited support from government and the Department of Health
- Financial and resource constraints
- Few donors presently funding palliative care for children
- Palliative care for children is not integrated into children's health care services
- A lack of professionals trained and confident to provide palliative care to children
- Misconceptions by health professionals, including doctors and paediatricians, leading to late or the lack of referrals. As a result, children suffer unnecessarily.
- An overwhelming number of HIV infected and affected children with palliative care needs leading to limited provision to children with other conditions
- Limited availability, knowledge about and use of palliative care drugs for children making it harder to control pain and other distressing symptoms

Governments should ensure that:

- palliative care for children is integrated into all health care services for children
- palliative care for children is included in relevant health, welfare and educational policies
- there is a defined budget for palliative care for children

Donors should include palliative care for children in their funding strategies

Educational Institutions where health, welfare and theological training is provided should:

- Integrate palliative care for children into all undergraduate and post-graduate curricula
- Develop accredited training courses in paediatric palliative care

National and International **Palliative Care Associations** should:

- Appoint a person to be responsible for palliative care for children
- Include palliative care for children in their strategies
- Provide a budget for the development of services, education and advocacy for children
- Monitor the development and impact of palliative care for children within their region

Children's **palliative care providers** should:

- Promote public awareness of the needs and services required for children with life-limiting and life-threatening conditions
- Provide ongoing education in palliative care for children for staff and volunteers involved in children's care
- Provide support to caregivers to prevent "burn-out" developing
- Identify and support models of best –practice where supervised training can be provided
- Monitor and evaluate palliative care for children

Listening to the voice of the child

Children all have an individual story to tell made up of unique experiences and responses to these experiences. These stories need to be told. Arthur Frank says that 'listening is hard, but it is also a fundamental moral act... people give us the gift of their story, we give them the gift of listening'. As children's palliative care practitioners we need to create the opportunity for stories to be told as only then will our care be specific and focused on the needs and wishes of the child.

Meaning is made through speaking. **Children speak through play** and therefore a child-centred approach needs to include meeting children at their own level, creating an environment which is non-threatening and creating an opportunity to play and draw. Caregivers need to use language which is easily understood by the child with caring supportive gestures. Community caregivers, social workers, volunteers, professional nurses, play therapists, psychologists, occupational therapists, educators, cleaning and administrative staff... all need to **centralise the needs of the child**.



*'You matter because you are you. You matter to the last moment of your life, and we will do all we can.
Not only to help you die peacefully, but to live until you die.'*
Dame Cicely Saunders

A Brief History of Children's Palliative Care in SA

- 1982 The first ever children's hospice "Helen House" started by Sister Frances Dominica in Oxford, England from the experience of offering respite care to 2 year old Helen Worswick, who had a brain tumour.
- 1983 Children's Hospice International (CHI) founded by Ann Armstrong-Dailey in USA
- 1985 Hospital based children's palliative care service opened in St Mary's Hospital, New York
- 1986 Hospital based children's palliative care service opened at Great Ormond Street Hospital in London
- 1988 ACT (Association for Children's Palliative Care) was started by Sister Frances Dominica and Professor David Baum as a national resource and information centre in the UK
- 1994 Bloemfontein Children's Hospice started as part of Bloemfontein Hospice, together with training courses on pain and symptom management and bereavement in children
- 1996 Cotlands Hospice opened its doors in Johannesburg, South Africa
- 1997 Mohau Centre opened in Pretoria as a residential care facility for children infected with HIV/AIDS.
- 1998 St Nicholas Children's Hospice (now Sunflower House Children's Hospice) opened in Bloemfontein, South Africa
- 2000 Ingwavuma Orphan Care (now Isibani Sithemba) started by Dr Ann Dean in northern KZN
- 2001 Opening of Lambano Sanctuary in Pretoria to care for HIV positive children
- 2002 Founding of Children's Homes Outreach Medical Programme (CHOMP - now The Bigshoes Foundation) by Dr Michelle Meiring and Professor Gayle Sherman to address the needs of orphaned and abandoned children, especially those with HIV/AIDS
- 2003 Opening of a children's ward at Hospice Wits in Houghton in partnership with CHOMP (now Bigshoes)

- 2005 The International Children's Palliative Care Network (ICPCN) was founded under the auspices of ACT
- 2006 Joan Marston appointed as Paediatric Palliative Care Portfolio Manager of SA (HPCA) with funding from the Diana, Princess of Wales Memorial Fund and as chairperson of ICPCN
- 2007 Six children's palliative care pilot sites identified & salaries and training for nurses funded by the President's Emergency Plan for AIDS Relief (PEPFAR)
- Founding of Children's Hospice Soweto under the leadership of Barbara Campbell-Ker
 - Seed funding from The True Colours Trust used to launch the ICPCN website. ICPCN's administrative base moved to HPCA in South Africa and the employment of an International Information Officer based in South Africa
 - Children's Palliative Care Ward opened by Grahamstown Hospice at Settlers Hospice in Grahamstown
- 2008 With further funding from PEPFAR, the first HPCA Paediatric Palliative Care Officer appointed to assist with and monitor the development of 18 HPCA children's palliative care sites in South Africa
- Butterfly House Community Children's Palliative Care Centre opened in Paarl, Western Cape
- 2009 Appointment of a second HPCA Regional Paediatric Palliative Care Officer
- PEPFAR funding increased to support the development of 30 sites offering palliative care services to children
 - First ever Children's Palliative Care Conference held in Africa through a partnership between CHI, HPCA & ICPCN. The conference was held in Cape Town
 - Publication of the text book *Children's Palliative Care in Africa*, edited by Dr Justin Amery who had been the Medical Director of Helen House in Oxford and spent 2 years in Uganda, where he began a children's palliative care service
 - Launch of the Beacon 3 Country Project led by Joan Marston and funded by the Diana, Princess of Wales Memorial Fund in order to create 3 centres of excellence at Mildmay in Uganda, PASADA in Tanzania and HPCA in South Africa
- 2010 The Baobab Paediatric Palliative Care virtual resource centre launched
- Appointment of 2 new staff members to assist with training of the paediatric educational programme
 - A third paediatric officer appointed
 - Publication of the new HPCA Standards including standards relating to children in each section
 - A comprehensive palliative care assessment tool developed for use at sites working with children
 - Publication of this Fact Book on Children's Palliative Care in South Africa

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The Baobab Paediatric Palliative Care Website

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Paediatric Palliative Care Introductory Course (1 week)

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About the ICPCN

The idea for an International Children's Palliative Care Network (ICPCN) originally arose at the meeting of national hospice and palliative care associations (now the Worldwide Palliative Care Alliance (WPCA) in The Hague in 2003. It was recognised that it was important to ensure that the voice and experience of children's palliative care was heard alongside that of adult palliative care and that structured and co-ordinated approaches were taken to lobbying for children's and adult palliative care at an international, pan-national and national level.

The ICPCN was founded in 2005 as a collaborative to connect existing children's palliative care services and raise awareness of the need to develop children's palliative care across the globe. The founders of the ICPCN saw the need for a network whose strength would lie in the sharing of knowledge, good practice and expertise to enable and support agencies around the world to develop a range of dedicated children's palliative care services. They recognised that although every country was unique in its scale of provision, motivation and capacity to provide palliative care to children, it was possible for each to contribute and learn from the other. For instance, developing countries often have innovative projects to provide palliative care to children.

At the 2nd Global Summit for National hospice and Palliative Care Associations held in Seoul, South Korea in March 2005, the following statement was released:

“Children and adolescents with life-limiting conditions have very specific palliative care needs which are often different to those of adults. If these children's and adolescent's physical, emotional, social, spiritual and developmental needs are to be met, the carers require special knowledge and skills. We ask that the voice of these children and adolescents is heard, respected and acknowledged as part of the expression of hospice and palliative care world-wide.”

The vision of the ICPCN is to achieve worldwide the best quality of life and care for children and young people with life-limiting illnesses, their families and carers, through networking, advocacy and information sharing.

To learn more about the ICPCN, please visit our website at www.icpcn.org.uk



OPEN SOCIETY INSTITUTE

This book has been printed with generous funding from the Open Society Institute Palliative Care Initiative

This Fact Book is for anyone who wants more information about children's palliative care in South Africa.

While this first Fact Book has been developed for South Africa, the basic facts regarding palliative care for children, and children themselves, remain the same wherever children are in the world.

This is the first in a series that the ICPCN is developing for in-country use. We plan to provide Fact Books for other countries that can be used for advocacy with governments, donors and other organisations working within that specific context. The vision of the ICPCN is that all children with life-limiting and life-threatening conditions will have access to palliative care provided by trained and competent practitioners; and this is one of the many steps towards that vision.

Why should children suffer ?



icpcn

international children's
palliative care network