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BACKGROUND

Health services for children need to accommodate preventive and promotive programmes to ensure the wellbeing of all children as well as curative and care programmes for those children who develop acute or long term health conditions.

Long term health conditions encompass a variety of problems that are ongoing or recurrent; impact on the life of the individual; and are usually incurable although interventions may minimize or ameliorate the impact of the condition on the affected individual and their family.

The impact of long term health conditions, as well as their treatment, is often pervasive affecting the physical, mental, emotional and social wellbeing of the individual as well as their participation in family and community life.

Whilst the prevalence of long term health conditions in childhood is unknown estimates of the burden of disease do exist for all age groups and countries. According to the WHO Global Health Estimates¹ the burden of diseases is reflected as Disability Adjusted Life Years (DALYs) and the proportion of DALYs due to non-communicable or chronic, long term health conditions in 2020 globally and in South Africa is reflected below:

	Global	South Africa
Under-5 years	10.9%	8.1%
5 – 14 years	31.1%	32.0%

Simplistically this suggests that long term health conditions account for a twelfth of the burden of ill health in young children but a massive third of the burden of disease in older children.

Ideally the optimal care of these children should be both holistic, addressing the needs of the entire child (physical, mental, emotional, social and spiritual) and their immediate family, as well as comprehensive, inclusive of the primary condition, all co-morbidities and complications arising from the condition and its treatment.

The quality of the care provided to children with three common long term health conditions (Asthma, Cerebral Palsy and Epilepsy) in KwaZulu-Natal was assessed during the 2018 accreditation of outpatient services in all general hospitals. The average score of audits of the clinical records of children with these conditions was 57.3% (range 29% - 86%) which suggests extremely limited care lacking both the holistic and comprehensive components to which these children are entitled.

A shift from disease-centered to child-centered care that is both comprehensive and holistic is therefore urgently needed in this province to ensure that children with long term health

¹ <https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/global-health-estimates-leading-causes-of-dalys>

conditions receive an acceptable quality and standard of care. This care is best achieved by ensuring that all hospitals and health care professionals working with children understand and are able to provide palliative care.

PALLIATIVE CARE

The focus of palliative care is NOT restricted to hospice or end-of-life care but rather to ease all suffering related to acute, long term or terminal health conditions.

Interventions to achieve need to encompass three broad concepts:

1. The indication – whilst palliative care aims to ease all health related suffering, acute conditions tend to be short-lived and in reality the primary target is children with
 - a. Life threatening conditions; or
 - b. Life limiting conditions, ie long term health conditions that may reduce the lifespan of the child and limit their lifestyle or activity.
2. The target of care includes the child and their family.
3. The care must be:
 - a. Holistic and address the physical, mental, psychological, social and spiritual needs of the child; and
 - b. Comprehensive with preventive, promotive, care and rehabilitation elements related to the primary condition as well as comorbidities, complications and the effects of treatment.
 - c. Continuous from the time of diagnosis, alongside curative or disease-modifying measures and include support for the family after the death of the child.

PACKAGE OF SERVICES

The package of palliative care services is similar across all levels of care.

However, the initial diagnosis or care of the primary condition, comorbidities or evolving complications may require referral to a higher level of care.

A comprehensive package should include 4 steps:

1. Identifying children who need palliative care
This should occur once the health professional appreciates the life threatening or limiting nature of the child's condition or the diagnosis of such a condition is confirmed.

Examples of children and/or conditions requiring paediatric palliative care are included in the table below.

POPULATION	EXAMPLES
Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Children with chronic life-threatening conditions that may be cured or controlled for a long period but that may also cause death	Malignancies, multidrug resistant tuberculosis, HIV/AIDS
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal muscular atrophy, Duchenne's muscular dystrophy
Children with severe neurological conditions that are not progressive but may cause deterioration and death	Static encephalopathy, spastic quadriplegia, spina bifida
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Family members of a fetus or child who dies unexpectedly	Fetal demise, hypoxic ischaemic encephalopathy, overwhelming sepsis in a previously healthy child, trauma from motor vehicle accidents, burns....

Source: Downing et al. 2016 (29); Wood et al. 2010 (30).

2. Assessment

Once a terminal or long term health condition has been diagnosed a comprehensive assessment by a multidisciplinary team is required.

This assessment should include an evaluation of:

- The growth and development of the child;
- The status of:
 - The primary condition;
 - All comorbidities;
 - Any complications.
- The impact of the disease, and treatment, on:
 - The child's emotional, spiritual and social wellbeing and schooling;
 - The family, including siblings;

3. Development of a management plan:

The multidisciplinary team needs to develop a management plan inclusive of:

- Drug treatment for:
 - The primary conditions; as well as
 - Symptom control – pain, constipation, mood (anxiety and/or depression), nausea & vomiting, itch, secretions etc
- Procedures:
 - As treatment;
 - To facilitate treatment; or
 - To improve comfort.

- Non-drug treatment:
 - Physical care and activities of daily living;
 - Nutritional support;
 - Education and counselling around the diagnosis, prognosis and management;
 - Counselling and psychosocial support;
 - Stimulation, education and socialization.

 - Psychosocial support:
 - To both the child and the family.
4. Implementation of the management plan:
- This should occur as close to home as possible.
 - The treatment plan is usually developed at the level of care where the diagnosis is confirmed.
 - Some components of this plan can only be implemented at that level – usually procedures as well as some drugs.
 - The remainder of the plan especially ongoing care, non-drug treatment and psychosocial support should be referred to a multidisciplinary team at a facility as close to the child's home as possible.

Referral criteria:

Referral to a higher level of care usually relate to the primary condition, comorbidities and all complications.

Reasons for referral to a higher level of care:

- To make a diagnosis or identify the underlying cause of a condition;
- To access modalities of care not available at the lower level of care;
- Poor response to treatment;
- Actual or anticipated deterioration in clinical conditions;
- Development of complications.

Reasons for referral to a lower level of care:

- Implementation of management plan;
- Ongoing monitoring, care and support;
- To be as close to home as possible.

ESTABLISHING A PALLIATIVE CARE SERVICE FOR CHILDREN

Although palliative care should occur within the normal child health services the following additional resources or skills are recommended.

Infrastructure (See Appendix 2 for specifications)

1. Facility Side ward or double cubicle with space for 2 beds;
 Access to an en-suite bathroom;
 Counselling room.

2. Equipment Equipment for a high care bed;
 Ambulatory syringe driver/pump;
 “Lazyboy” type chair;
 Pressure-reducing mattresses;
 Opioid lock box.
 Toys, books and stationery.

Resources (See Appendix 3 for a detailed list of essential requirements)

1. Pharmaceuticals as per the Paediatric Essential Drug List and level of care.
Drugs listed in Appendix 3 should be considered the minimum requirement for a paediatric palliative care service.

2. Surgical sundries and consumables according to the level of care.
Items listed in appendix 3 should be considered essential requirements for a paediatric palliative care service.

3. Management Protocols/Guidelines.
Clinical guidelines appropriate to the specific conditions;
Standardised clinical record templates for long term health conditions;
Guidelines on Paediatric Palliative Care.

4. Community resources.
A list of national and provincial organisations able to assist with the implementation of palliative care services is included in Appendix 3;
A list of similar organisations in and around each facility must be compiled by the facility paediatric palliative care champion(s) to complement the national and provincial lists.

Staff

A paediatric palliative care champion who can be a doctor, a nurse or a therapist.

A multidisciplinary team comprising some or all of the following cadres:

- Doctor;
- Nurse;
- Therapist;
- Social worker;
- Psychologist.

Skills

All members of the paediatric palliative care team should have exposure to paediatric palliative care training.

Available training options are presented in Appendix 4.

WAY FORWARD

Paediatric palliative care services are required in all health facilities caring for children regardless of the level of care of the facility.

These services must be established through a change in clinical practices and using existing resources and staff.

This will be achieved through:

1. Establishing an Area paediatric palliative care team at each tertiary hospital in KZN to facilitate and support the implementation of paediatric palliative care services in each hospital in their respective catchment areas.
2. Conducting sensitization workshops in each district to expose the management and clinicians in each facility to the need and benefits of paediatric palliative care and the process required to establish such a service in their facility.
3. Identifying a paediatric palliative care champion(s) in each facility.
4. Providing in-service training on paediatric palliative care for champions and multidisciplinary teams.
5. Facilitating and supporting the development of paediatric palliative care services in each hospital in KwaZulu-Natal.

REQUIREMENTS FOR PAEDIATRIC PALLIATIVE CARE

- The package of palliative care services and the requirements to provide this are similar across all levels of care;
- The assessment and treatment of the primary condition depends on the complexity of the condition and will differ between levels of care;
- Referral to higher levels of care is thus determined by the primary condition.

LEVEL	PACKAGE	PROVIDER	INFRASTRUCTURE	RESOURCES	MONITORING
All levels of care	Recognition Assessment Management plan <ul style="list-style-type: none"> • Drug • Procedures • Non-drug • Psychosocial support Ongoing care <ul style="list-style-type: none"> • Implement plan • Monitor and support 	All clinical health professionals 1 or more champions MDT with <ul style="list-style-type: none"> • Doctor • Nurse • Therapist • Social worker • Psychologist 	Facility <ul style="list-style-type: none"> • Side ward • Space/bed for parent Equipment <ul style="list-style-type: none"> • As a high care bed 	Surgical sundries Pharmaceuticals Management protocols / STGs Community resources	Availability of service <ul style="list-style-type: none"> • Credentialing Utilization <ul style="list-style-type: none"> • Referrals to Social Worker Clinical care – 3 ⁰ services only <ul style="list-style-type: none"> • Clinical audit



NB A functional paediatric palliative care services requires access to the following infrastructure on an ad hoc basis.

FACILITIES

Access to a sideward or cubicle with an en-suite bathroom and capacity for 2 beds.

Size:	5.4 x 3.2 m Minimum 15 m ²
Placement:	Close to nurse's station Area of visual and auditory privacy
Services:	Clinical hand basin Oxygen, medical air, vacuum & 4 electrical sockets per bed Dimmable general lighting Spot light Child friendly fittings and appropriate placement
En-suite:	Hand basin Toilet Bath

EQUIPMENT

1	Cot – large / Juvenile bed
1	Adult bed / “Lazyboy” chair for parent
1	Locker
1	Cardiac table
1	Stool / chair
1	Stethoscope
1	O ₂ blender
1	Double O ₂ flow meter
1	Suction unit
2	Infusion pump
2	Syringe pump
2	“Drip stand”
1	Feeding pump
1	Multi-parameter monitor (T ^o , pulse, resp, SpO ₂ , NIBP)
1	Heated humidified high flow oxygen/air
Ambulatory syringe driver / pump	1 per district hospital 2 per regional / tertiary hospital



The following are required to support the effective implementation of a paediatric palliative care service.

SURGICAL SUNDRIES

The following surgical sundries are considered essential and a minimum ward stock is required at all times:

- Nasogastric drainage and feeding tubes;
- Urinary catheters;
- Flashlights with rechargeable batteries (if no access to electricity);
- Diapers (baby and adult) or cotton and plastic;
- 20 ml Luer-lock syringes;
- Butterfly needles 23 Gauge;
- Infusion sets;
- Suction equipment (wall or electric) including catheters;
- Wound care supplies.

PHARMACEUTICALS

The following drugs are considered essential and should be available at district hospitals:

- Amitriptyline, oral;
- Atropine eye drop solution 0.5-1%, oral;
- Carbamazepine, oral;
- Cetrizine, oral;
- Chlorhexidine 0.2% mouthwash;
- Chlorpheniramine, oral and injectable;
- Clotrimazole 2% cream;
- Dexamethasone, oral and injectable;
- Diazepam, oral and injectable;
- EMLA cream 5% (lidocaine/prilocaine);
- Fluconazole, oral;
- Fluoxetine (sertraline or citalopram), oral (>8 years old);
- Furosemide, oral and injectable;
- Haloperidol, oral and injectable;
- Hyoscine butylbromide, oral and injectable;
- Ibuprofen, oral (>3 months old);
- Lactulose (sorbitol or polyethylene glycol), oral;
- Lamotrigine, oral;
- Liquid paraffin, oral;
- Lidocaine 2% gel;
- Loperamide, oral;
- Lorazepam, injectable and sublingual;
- Metoclopramide, oral and injectable (>1 month old);

- Metronidazole, oral, to be crushed for topical use;
- Midazolam, injectable and sublingual;
- Morphine, oral immediate release and injectable;
- Morphine, oral slow release;
- Naloxone, injectable;
- Omeprazole, oral;
- Paracetamol, oral;
- Petroleum jelly.
- Phenobarbitone, oral and injectable;
- Phenytoin, oral and injectable;
- Sodium valproate, oral;
- Spironolactone, oral;
- Tramadol, oral;
- Zinc and castor oil cream.

CLINICAL PROTOCOLS/STANDARD TREATMENT GUIDELINES

National Department of Health Paediatric Essential Drug List and Standard Treatment Guidelines

<https://www.knowledgehub.org.za/elibrary/hospital-level-paediatrics-standard-treatment-guidelines-and-essential-medicines-list>

Chapter 19 Pain control

Chapter 20 Palliative Care

The Association of Paediatric Palliative Medicine (APPM) - Formulary

<https://appm.org.uk/guidelines-resources/appm-master-formulary/>

COMMUNITY RESOURCES

The following organisations are able to offer support/ advice:

1. National

- PatchSA
<https://patchsa.org>
- The Association of Paediatric Palliative Medicine (APPM) - Formulary
<https://appm.org.uk>
<https://appm.org.uk/guidelines-resources/appm-master-formulary/>

2. Provincial

- Umduduzi – Hospice Care for Children
Dr Julia Ambler 0764178977 / julia@umduduzi.co.za; or
Tracey Brand 083695164 / tracey@umduduzi.co.za
- Butterfly House
Tarryn Bell 0712773861 / tbellnr1@gmail.com

3. Local

- Hospice Association of KwaZulu-Natal

HOSPICE	CONTACT PERSON	CONTACT DETAILS	ADDRESS
Blessed Gérard's Hospice	Sven Anderson sven@bbg.org.za Carolyn Nunn carolyn@bbg.org.za	T +27 32 4562743 F +27 32 4567962	P.O. Box 440 Mandini 4490 www.bbg.org.za
Chatsworth Hospice	Mrs Kogi Singh kochet185@gmail.com manager@chatshospice.co.za	T +27 31 4032273 F +27 31 4032417	P.O. Box 56198 Chatsworth 4030 www.chatshospice.co.za
Duduza Care Centre	Sr. Colette Mthimkhulu +27 78 150 2946 (CELL) dudrat@trustnet.co.za dudadmin@trustnet.co.za	T +27 34 6511 722 F +27 34 65 11 096	Maria Ratschitz Mission P.O. Box 194 Wasbank, 2920
Estcourt Hospice	Rena Licen esthospice5@lantic.net	T+27 36 352 5634 F+27 36 352 6203	P.O. Box 75 Estcourt 3310
Highway Hospice	Linda Webb lmwebb@hospice.co.za medical@hospice.co.za	T +27 31 2086110 F +27 31 2082945	P.O. Box 28 Westville 3630 www.hospice.co.za
Hillcrest AIDS Centre Trust (HACT)	Candace Davidson ceo@hillaims.org.za	T +27 31 765 5866 F +27 31 765 8781	PO Box 2474 Hillcrest 3650 www.hillaims.org.za
Holy Cross Hospice	Priscilla Dlamini priscd@holycrosshospice.org.za info.manager@holycrosshospice.org.za admin@holycrosshospice.org.za	T +27 35 3374878 C +27 837255918 F +27 35 3374118 F2E +27 866429976	P.O. Box 928 Gingindlovu 3800 www.holycrosshospice.org.za
Howick Hospice	Sharon Nugent gm@howickhospice.org.za Charlotte Woudberg clinicalmanager@howickhospice.org.za	T +27 33 3305257 F +27 33 3305257	P.O. Box 819 Howick 3290 www.howickhospice.org.za
Isibani Sethemba	Kenneth Macheri +27 78 9202926 kenneth@orphancare.org.za	T +27 35 5910793 F +27 35 5910794	P.O. Box 272 Ingwavuma 3968
Khanya Hospice	Neil McDonald +27 39 9731783 (Direct Line) neil@scottnet.co.za manager@khanyahospice.org.za	T +27 39 9730277	P.O. Box 144 Umkomaas 4170 http://khanyahospice.org.za/
Ladysmith Hospice	Chandre Jannon c.jannon@telkomsa.net Marina Smit nkrhospice@webafrica.org.za	T +27 36 6312697 F +27 36 6313908	P.O. Box 2810 Ladysmith 3370
Maskey Health Services	Doris Cele maskeyhealth@telkomsa.net doriscele1@gmail.com Nokwazi Sikhakhane nokwaziesikhakhane@gmail.com	T +27 31 9062343 C +27 823153660 F +27 31 9063867	R831 Umlazi Township Umlazi 4031
Msunduzi Hospice	Warren Oxford-Huggett warren@hospicekzn.co.za pcmanager@hospicekzn.co.za	T +27 33 3441560 F +27 33 3442892	P.O. Box 22023 Mayor's Walk 3208 www.hospicekzn.co.za

HOSPICE	CONTACT PERSON	CONTACT DETAILS	ADDRESS
Philanjalo Hospice	Dr Tony Moll 4tonymoll@gmail.com	T +27 33 4930429	P.O. Box 195 Tugela Ferry 3010 www.philanjalo.org.za
South Coast Hospice	Diane Van Dyk diane@schospice.co.za Shamila Clothier shamila@schospice.co.za	T +27 39 6823031 F +27 39 6825391	P.O. Box 504 Port Shepstone 4240 www.southcoasthospice.co.za
Tender Loving Care Home Services	Helen Patrick tlhospice@kokstad.co.za	T +27 39 7274078 F2E +27 867754946	P.O. Box 44011 Kokstad 4700
Themba lethu Care Organisation	Betsy Meyer betsy@ourhope.org.za Xoli Msimanga xoli@ourhope.org.za	T +27 835105562 F +27 866473346	PO Box 49 Winterton 3340 http://www.ourhope.org.za/
Verulam Regional Hospice	Prof. C. Kistan kistanc@gmail.com Dr. Danny Chetty dannychetty61@gmail.com	T +27 32 5332764 F +27 32 5330486	P.O. Box 71 Verulam 4340 http://vlmhospice.co.za/wp/
Vryheid Hospice	Cecelia van Wyk vryhosp2@telkomsa.net	T +27 34 9809888 F +27 34 9809888	P.O. Box 210 Vryheid 3100
Vulamehlo	Elizabeth Kumalo Purity Mqwebu vulamehlohr@telkomsa.net	T +27 32 5596271 F +27 32 5596271	P.O. Box 2782 Kwa-Dukuza 4449
Zululand Hospice	Christiana Samuel manager@zululandhospice.org.za Jane Ashburner nursemp@zululandhospice.org.za	T +27 35 7724953 F +27 35 7724910	P.O. Box 62 Empangeni 3880



The following courses are available to assist staff to gain insight, knowledge and understanding of paediatric palliative care.

IN-SERVICE COURSES:

Introduction to Children's Palliative Care

Provider:	Umduduzi
Venue:	Self-study
Duration:	5 hours
Trainers:	4
Participants:	Unlimited Champions & any other interested people
Style:	Blended Learning
Equipment:	Computer and internet access
Costs:	Course materials

Key Components of Children's Palliative Care

Provider:	Umduduzi
Venue:	Health facility
Duration:	3 days
Trainers:	4
Participants:	20 Must have achieved > 80% in the Introduction Course
Style:	Face-to-face
Equipment:	Computers, data projector, whiteboard and markers
Costs:	Course materials – R150 / person Refreshments – R 100 / person / day Accommodation & Travel

ON-LINE COURSES:

Patch Academy

<https://patchsa.org/patch-academy/>

Self-study based on "*Palliative Care for Children: a guide for improving the quality of life of patients and their families.*"

Readings, activities, quizzes and videos

Courses:

- Introducing Children's Palliative Care – FREE
- Communication in Children's Palliative Care – R350
- Assessing & Managing Children's Pain – R350
- Teamwork, Managing Conflict & Self-Care – R350
- Cultural Competency & Spiritual Care – R350
- Supporting Grieving Children in the time of COVID 19 – FREE

ICPCN e-Learning

<https://www.icpcn.org/icpcns-elearning-programme/>

Self-study via e-learning

Theory, clinical work and assessments

No cost

Courses:

- Introduction to children's palliative care
- Pain assessment and management for children
- Childhood development and play in children's palliative care
- Communicating with children and emotional issues in children's palliative care
- End of life care in children's palliative care
- Grief and bereavement in children's palliative care
- Neonatal palliative care – an introduction
- Symptoms other than pain
- Adopting a children's palliative care approach to the COVID-19 Pandemic

UNIVERSITY COURSES

University of Cape Town

Short course:	Palliative care
	: http://www.ceuhealth.uct.ac.za/introduction-palliative-care
Provider:	Hospice Palliative Care Association
Requirements:	Degree or diploma in primary discipline
Venue:	On line e-learning
Duration:	16 weeks 1 st semester
Style:	8 modules requiring 5 hours learning & studying over 2 weeks
CPD points	30
Cost:	R 6 000.00

Short course:	Providing Healthcare for Children with Long Term Health Conditions (LTHC)
	: http://www.ceuhealth.uct.ac.za/providing-healthcare-children-long-term-health-condition-lthc
Provider:	Department of Paediatrics & Child Health
Requirements:	Health professional
Venue:	On line e-learning
Duration:	4 days
CPD points	24
Cost:	R 4 800.00

Stellenbosch University

Short course:	Palliative care
Provider:	Division of Family Medicine and Primary Care
Venue:	On line
Duration:	12 weeks 2 nd semester
Style:	Self-study, synchronous & asynchronous discussion groups, assessments & 2 assignments
Cost:	R 6 600.00



Indicators to monitor paediatric palliative care services:

1. Capacity of health system – annual assessment.

Proportion of hospitals that are providing paediatric palliative care

Numerator N^o of hospitals with an established paediatric palliative care MDT

Denominator N^o of general hospitals

2. Utilization of service – monthly.

Number of children with disability or long term health conditions referred to the Social Worker

3. Quality of care.

- i. All hospitals:

Average monthly score on clinical audit for long term health conditions – documented in paediatric dashboard – Tool 20 “Pediatric Record Audit Scores”

- ii. Tertiary and select regional hospitals:

6-monthly clinical audit of “Advance Care Plans”