Guidebook for caregivers of children receiving palliative care in Kenya

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My child matters

How to use this guidebook

Caregivers

- This guide was put together based on feedback from caregivers and palliative care professionals taking care of children with palliative care needs in Kenya. It is designed to help carers of children receiving palliative care cope through the treatment journey.
- The term children's palliative care and paediatric palliative care may be used interchangeably with the same meaning.
- The guide can be used by parents, teachers, caregivers and communities supporting children with life threatening conditions.
- It is divided into chapters that focus on key areas of concern to carers and one can read based on their area of need.

Children

- This section focuses on children and gives information on what the child should expect while receiving care. It highlights the benefits of palliative care for children.
- If the child is old enough, the carer may allow them to read/view it themselves with their guidance. How to read to the child:
    - *Use a pace that is suitable for the child*
    - *Show the images while reading*
    - *Allow for questions and comments from child (reflection)*
    - *Role-playing activities to express feelings*
    - *A child can draw their feelings, scenarios etc on a separate piece of paper as a way to express themselves and give the caregiver an idea of how they feel about a certain topic or how they are feeling at that moment/point*

How to access palliative care services if not yet enrolled:

- *Talk to your health provider to link your child to a palliative care professional. Consent is required from you to receive these services.*
- *Refer to https://kehpca.org/pc-providers/ for a comprehensive list of palliative care centres in Kenya according to counties.*

Your health provider will give you information on the cost of services and extent of cover by insurance like SHA (Social Health Authority) or private insurance.

More information on children's palliative care may be accessed from www.kehpca.org or www.icpcn.org

Table of contents

01 **What is palliative care?**

Key facts about palliative care for children (WHO)*

DEFINITION: Palliative care for children is 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 homes.*
- *The care also focuses on the siblings.*

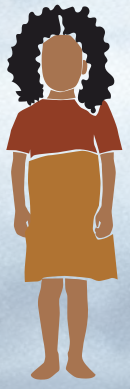
Which conditions require palliative care services? Cancer, HIV-AIDS, genetic disorders, severe cerebral palsy, neurodegenerative diseases, complex congenital heart diseases, lung conditions, metabolic diseases, cystic fibrosis, prematurity, severe congenital anomalies, and certain chromosomal alterations are some of the life-threatening and/or limiting diseases or conditions that may benefit from palliative care.

The aim of palliative care is to give patients the best quality of life possible.

Palliative care relieves suffering and improves quality of life for patients and families dealing with any type of life-threatening illness.

Palliative care is about helping people maintain quality of life through practical help, physical care, medicines, and spiritual and emotional support.

Palliative care is for children and adults. It is not only about the end of life. It can be considered early in a disease to help improve troubling symptoms.



Source: World Health Organization

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* https://www.who.int/europe/news-room/fact-sheets/item/palliative-care-for-children

What are the goals of paediatric palliative care?

- To prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, optimising pain and symptom management.
- Help patients with life-threatening/ life-limiting conditions and their families live as normally as possible.
- Provide continuity of care – supporting families during hospitalisation and coordinating discharge with the medical team, follow up with special needs clinic as appropriate.
- Provide patients and their families with timely and accurate information.
- Support patients and families in decision-making and goal setting.
- Promoting hope and dignity for patients and families.
- Caring for the whole family by listening, respecting their beliefs and recognizing each family and child is different.

02 Myths vs facts about palliative care

MYTH

Having hospice or palliative care means I will die soon...

FACT

Hospice or palliative care is not just for the end of life.

MYTH

Palliative care is only provided in a hospice or hospital set up...

FACT

Palliative care can be provided anywhere - at home or a long-term care facility like a hospice or a hospital.

MYTH

Morphine causes death

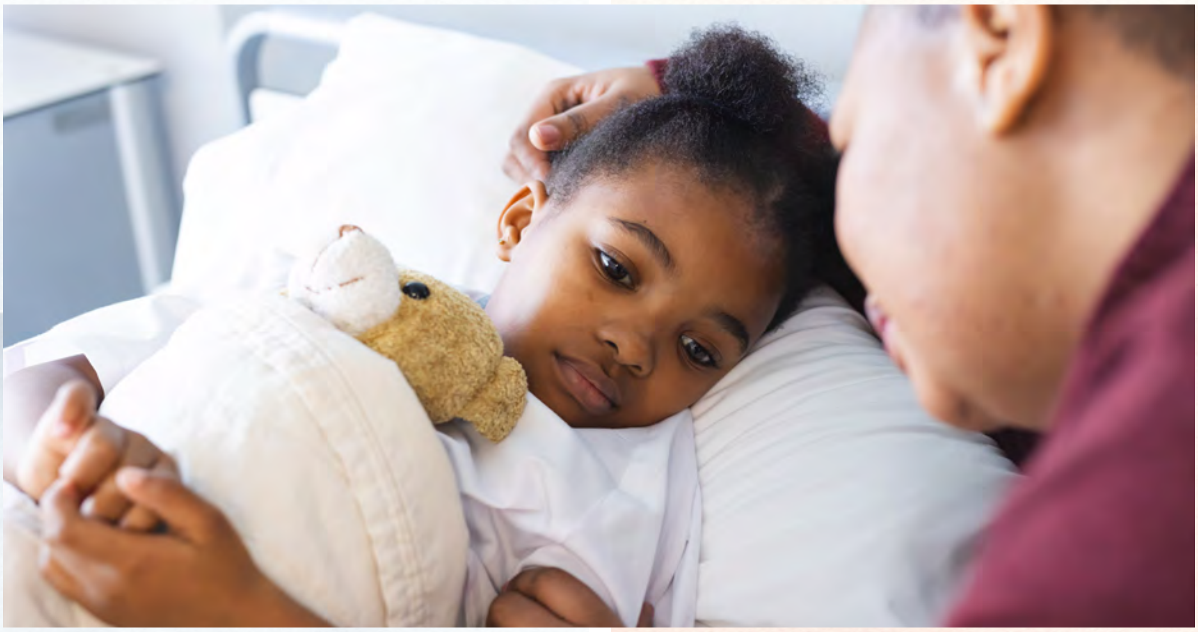
FACT

Morphine is an effective pain reliever for severe pain

Myths about pain in children

- ⊗ *Infants are neurologically immature and therefore cannot conduct pain impulses*
- ✓ **Truth:** Infants also experience pain and hence require pain relief
- ⊗ *Infants do not remember pain, because of cortical immaturity*
- ✓ **Truth:** It is important to relieve infants' pain as it may negatively impact on how they perceive pain when older
- ⊗ *Children do not report pain while playing or sleeping so they must get over it quickly or not be experiencing it*
- ✓ **Truth:** Pain assessment in children should be continuous and relief therapies given regularly
- ⊗ *Children should not be given opioids like morphine for pain relief*
- ✓ **Truth:** Morphine is a safe medication prescribed for children

Paediatric palliative care



Palliative care teams treat:

1. Children with heavy burden symptoms
2. Children with complex decisional support needs
3. Children with large treatment teams
4. Children with chronic conditions
5. Children undergoing curative treatment
6. Children at the end of life

Do not be afraid to refer children to palliative care - they have better outcomes if referred early!

Common misconceptions:

1. Consulting palliative care does not guarantee do-not-resuscitate 'DNR' status for a patient
2. Palliative care teams provide families with a lot of support but might not be able to give a family access to all desired resources
3. Palliative care physicians are not "death doctors"! Hospice care is only one area of their work

Paediatric palliative care is not limited to end of life care and can provide great relief from pain and discomfort!

Source of information for this section: Adapted from https://thecurbsiders.com/cribsiders-podcast/62

03 **Impact on caregiver**

Introduction

The number of children with life-threatening conditions is increasing. Children’s palliative care is a relatively young discipline in Kenya whose service uptake is still low. According to the Kenya Palliative Care Policy 2021-2030, less than 5% of children with palliative care need access to these services. In children, palliative care begins at diagnosis and is delivered alongside other treatments. Consequently, these children may receive palliative care for long periods of time, often over the course of many years.

<5% **of children in need of palliative care require access to these services**

As a caregiver of such a child, one may have had to assume a heavy caring role including the management of breathing support, specialised feeding and the administration of multiple medications.

Further, the caregiver may be required to balance additional responsibilities such as managing busy appointment schedules, negotiating complex decision making, supporting education, providing transport, alongside fulfilling family and social responsibilities. These responsibilities are ever present for whoever may be the child’s primary caregiver.

> ***Current evidence shows that carers of children with life threatening conditions are more likely to experience poor physical, psychological and spiritual health outcomes.***

Source of information for section 3: Adapted from research paper- Engel M, Brouwer MA, Jansen N, Leget C, Teunissen SC, Kars MC. The spiritual dimension of parenting a child with a life-limiting or life-threatening condition: A mixed-methods systematic review. *Palliat Med. 2023* Oct;37(9):1303-1325. http://doi.org/10.1177/02692163231186173. Epub 2023 Jul 17. PMID: 37461310; PMCID: PMC10548770.

Physical effects

Some of the physical effects you may experience while caring for a child with life-threatening or life-limiting illness include but are not limited to;

- *Back pain*
- *Body aches*
- *Sleep disturbances*
- *Tendency to engage in unhealthy coping behaviour such as binge drinking, chain smoking or indulging in illegal drugs and substance abuse*
- *Heart disease or even stroke from anxiety and constant stress*

Psychosocial effects

These include but are not limited to;

1. *Stress*
2. *Anxiety*
3. *Depression*
4. *Memory lapses and losses caused by burn out and inadequate sleep*
5. *Financial difficulties and stress*
6. *Conflicts in interpersonal relationships*
7. *Breakage or breakdown of families*
8. *Alienation from friends and extended family members*
9. *Inadequate care and attention to the needs of other family members, including the siblings of the ailing child*

Source of information for section 3: Adapted from research paper- Engel M, Brouwer MA, Jansen N, Leget C, Teunissen SC, Kars MC. The spiritual dimension of parenting a child with a life-limiting or life-threatening condition: A mixed-methods systematic review. *Palliat Med. 2023* Oct;37(9):1303-1325. http://doi.org/10.1177/02692163231186173. Epub 2023 Jul 17. PMID: 37461310; PMCID: PMC10548770.

Spiritual effects

As a caregiver to a child or a young person that is living with a life-threatening or life-limiting illness, you may experience challenges to your spirituality that include;

- *Self-blame for the condition of the child*
- *Decreased urge to join in religious activities that you previously engaged in and enjoyed*
- *Feelings of loneliness and disconnectedness*
- *Confusion and inner conflicts*
- *Feelings of abandonment by a higher power that you believe in, amongst other things*

It is important to take note that all the feelings you have are valid, and you should not be ashamed of feeling the way you do.

There are other caregivers who have lived through similar or almost similar experiences as you are currently undergoing, and have had the courage to write down some words of encouragement or have been gracious to share their testimonies for the sake of others who could be going through similar experiences.

As a message of encourangement, please take a look at this testimonial (a positive story) on this link*, from a real family who have undergone similar experiences.

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* https://courageousparentsnetwork.org/featured-families/numbers-family-faces-a-diagnosis-of-severe-aplastic-anemia

Source of information for section 3: Adapted from research paper- Engel M, Brouwer MA, Jansen N, Leget C, Teunissen SC, Kars MC. The spiritual dimension of parenting a child with a life-limiting or life-threatening condition: A mixed-methods systematic review. *Palliat Med. 2023* Oct;37(9):1303-1325. http://doi.org/10.1177/02692163231186173. Epub 2023 Jul 17. PMID: 37461310; PMCID: PMC10548770.

04 **Tips on self care**

Introduction

It's easy to view self-care as a low priority when your child is diagnosed with a serious illness. Your role as a parent and parenting partner has unexpectedly changed. The child has urgent and complex medical needs; you must manage appointments and service providers, and learn new information about disease and medical treatment—all while tending to the needs of other family members, work and/or other responsibilities. Making time for yourself may be the first thing to go.*

Self care is care provided *"for you, by you."* It's about identifying your own needs and taking steps to meet them. It is taking the time to do some of the activities that nurture you. Self care is about taking proper care of yourself and treating yourself as kindly as you treat others.

> ***Self care therefore is an active choice to participate in activities that are known to increase holistic well-being.***

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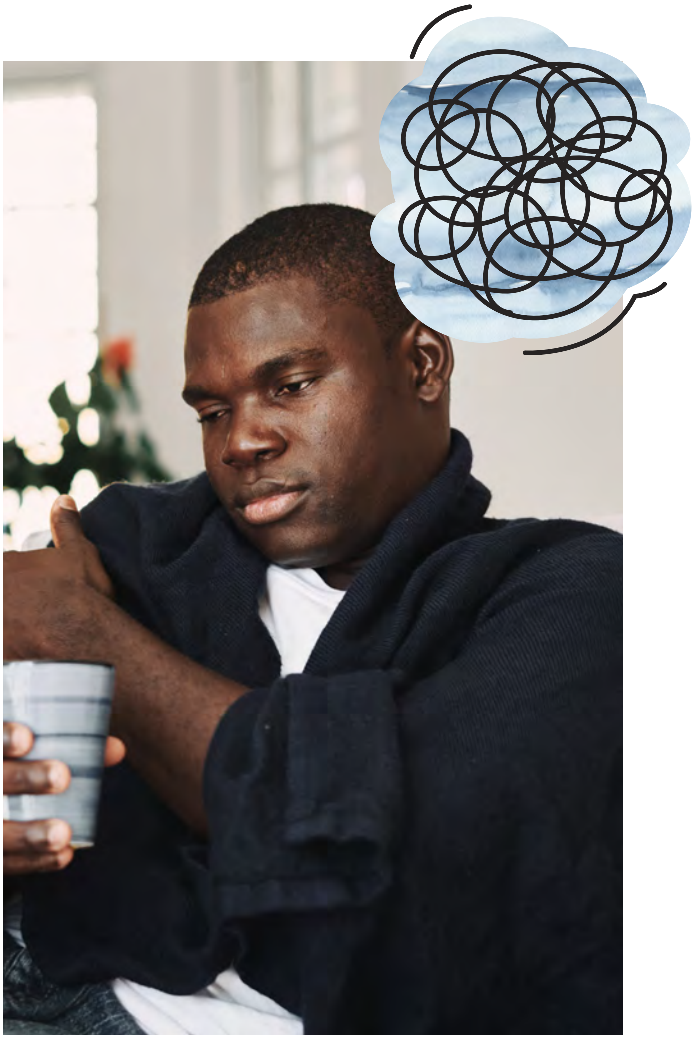
* https://api.courageousparentsnetwork.org/app/uploads/2017/10/CPN-SelfCare-2.pdf

Source of information for section 4: Adapted from https://iris.paho.org/bitstream/handle/10665.2/58370/PAHONMHNVcvn5210040_eng.pdf?sequence=1&isAllowed=y



Myths about self-care

We sometimes push away taking care of ourselves with things we tell ourselves that aren't necessarily true. Here are some common examples:

- ⊗ *I can't leave my child's bedside*
- ⊗ *There's no one else to care for my child*
- ⊗ *I'm the only one who knows how to care for my child*
- ⊗ *I am the only one who can comfort my child*
- ⊗ *My child will feel abandoned if I leave them*
- ⊗ *Taking care of myself takes more time, or money, or resources than I have*
- ⊗ *It would be selfish of me to leave my child or my other children to do something for myself*
- ⊗ *I don't have time to take care of myself*

These thoughts are all natural and understandable, but it can help to consider if they are really true and see how you might change your point of view.

It may certainly be true that you are the person who makes your child feel most comfortable and safe. But that doesn't mean that you are the only person who can care for your child.

Children are more resilient than we think.

It is important for both you and your child that you are able to step away periodically. **Separation can be difficult, but it's normal and necessary, and healthy for both of you.** Your child might even enjoy the company and companionship of somebody new.

Your child doesn't necessarily feel abandoned when you step away. If they are cognitively aware, you may find it helpful to explain that you need to have some alone time every now and then, to help you be the best parent you can be.

Source of information for section 4: Adapted from https://iris.paho.org/bitstream/handle/10665.2/58370/PAHONMHN-Vcvn5210040_eng.pdf?sequence=1&isAllowed=y

The following examples give pointers to self awareness that enables a caregiver to take stock of their lives. This can guide you to;

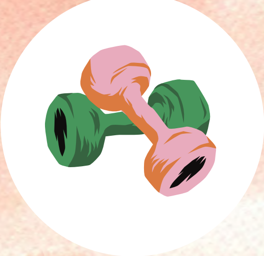
a. **Know when and at what point to take a break**
b. **Decide on how to do it e.g. plan on leaving the child under the custody of someone**
c. **Decide from whom and how to get help**
d. **Recognise stress and depression and how to manage them**

Ways to take care of yourself

Any time you make for yourself is a form of self-care and helps you be a more patient, calmer caregiver for your child and family. Even a few minutes a day can be rejuvenating. Here are some suggestions of ways to take care of yourself.

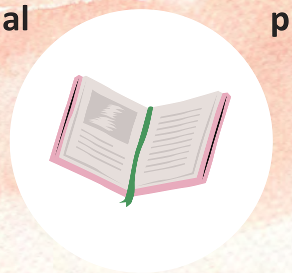
Types of **self care**

spiritual



physical

social



emotional

personal

Ways to take care of yourself

Rest

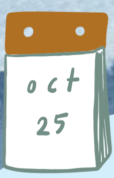
We all need sleep, and we especially need it under stressful conditions. With rest, we gain patience and perspective and are better able to solve problems.

Exercise and fresh air

Be active: go to the gym, go for a run, take a walk, swim, play tennis or golf, watch an online exercise video. Or just get outside and breathe in some fresh air for a few minutes.

Meditation

Sit in silence, or download a guided meditation or daily meditation app.



Talk therapy

If this is possible for you financially, talking to a neutral third party professional, such as a grief counsellor, psychologist, social worker or other therapist, can be a helpful relief. Spiritual leaders (Pastors, priests, imams, chaplains, etc.) are also excellent and wise listeners, and do not charge for their services. In talking to someone who is not your friend or family member, you can express the feelings, fears, and worries that you might not want to share with anyone else. A good therapist will help you recognize your strengths and find solutions to problems. Sometimes this resource will be available to you at no charge through palliative care or social workers.

Yoga/ stretches

The rigorous exercise or gentle stretching can be calming and energising. Take a class or watch an online video, for example.

Prayer

Some people are comforted by prayer, with or without a community or spiritual leader. You don't have to be religious to pray.

Friends

Taking care of a sick child can be isolating. Time with a friend helps reconnect you to your bigger world. Sharing your feelings with someone you trust helps you feel normal. And it can also be a relief to listen to someone else talk about their life.

Media

Movies and videos are all a great form of escape. Comedies are particularly good because they make you laugh, and laughter is always helpful. If you enjoy sports, watching your favourite athletes or rooting for your favourite teams can provide a sense of fun.

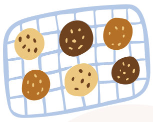
Ways to take care of yourself

A favourite treatment

Massage, acupuncture, manicure, pedicure or haircut can make you feel more normal and like yourself.

Support group

Support groups are available in many communities, and they are also conducted online. It can be helpful to talk your concerns through with other parents who understand what you are experiencing. Many disease groups also offer online discussion groups.



Play

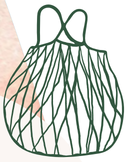
Spend time playing, snuggling and doing favourite activities.

Creative expression

If you like to write, putting your feelings and worries onto the page can be a relief. It can also help you process your experience. You will see how much you are doing, how hard you are trying, how good a parent you are to your child. Writing may also help you see where you are struggling and may need some extra help. On the other hand, writing about something not related to your child may provide just the relief you need. The same is true for dancing, drawing, painting, sculpting, quilting, scrapbooking, weaving and all other forms of creative expression. Making or just listening to music can also be very nourishing.

Ask for help*

Asking for help is a sign of strength and is a way to help you take care of yourself.



Shop

A little retail therapy might feel good. Just getting out of the house to browse can feel like a good change, even if you don't buy anything.

Eat well

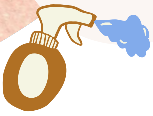
Food is a simple pleasure and is a gift you give yourself. It feeds your mind as well as your body. Good food makes you feel better and gives you energy to cope with everything you need to deal with. It helps to bring healthy snacks with you to the hospital for long appointments and inpatient stays. And treats—such as the occasional cupcake—can spark real joy.

Reconnect with your partner

A walk, ride, drive or even an occasional evening out can help you feel more connected. If the partnership is feeling fragile, you might consider talking together with a therapist.

Work

Work can also be a form of self care.



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* https://courageousparentsnetwork.org

The checklist below is a guide to help you (the caregiver) make an evaluation on yourself daily or weekly. Please evaluate yourself by ticking the points listed below.

Self care checklist

Today or some time this week I have:

- ♡ *Rested enough - 6-8 hrs at night*
- ♡ *Eaten well - nutritious healthy food*
- ♡ *Drunk enough water - 8 glasses*
- ♡ *Asked for or accepted help*
- ♡ *Managed my stress in a healthy way*
- ♡ *Talked to someone or a friend*
- ♡ *Meditated or taken deep breaths*
- ♡ *Prayed or spiritually practiced*
- ♡ *Watched or listened to something funny and enjoyable*
- ♡ *Done something fun or peaceful*
- ♡ *Been kind to myself*
- ♡ *Done stretches or excercised*
- ♡ *Practiced gratitude*
- ♡ *Connected with other caregivers for support*
- ♡ *Done something relaxing or spent time on myself*

CONCLUSION: It is not selfish to take care of yourself. The opposite is true: when you are healthy and strong, you are more resilient and better able to cope with the demands and responsibilities of your life.

05 **About the child's journey**

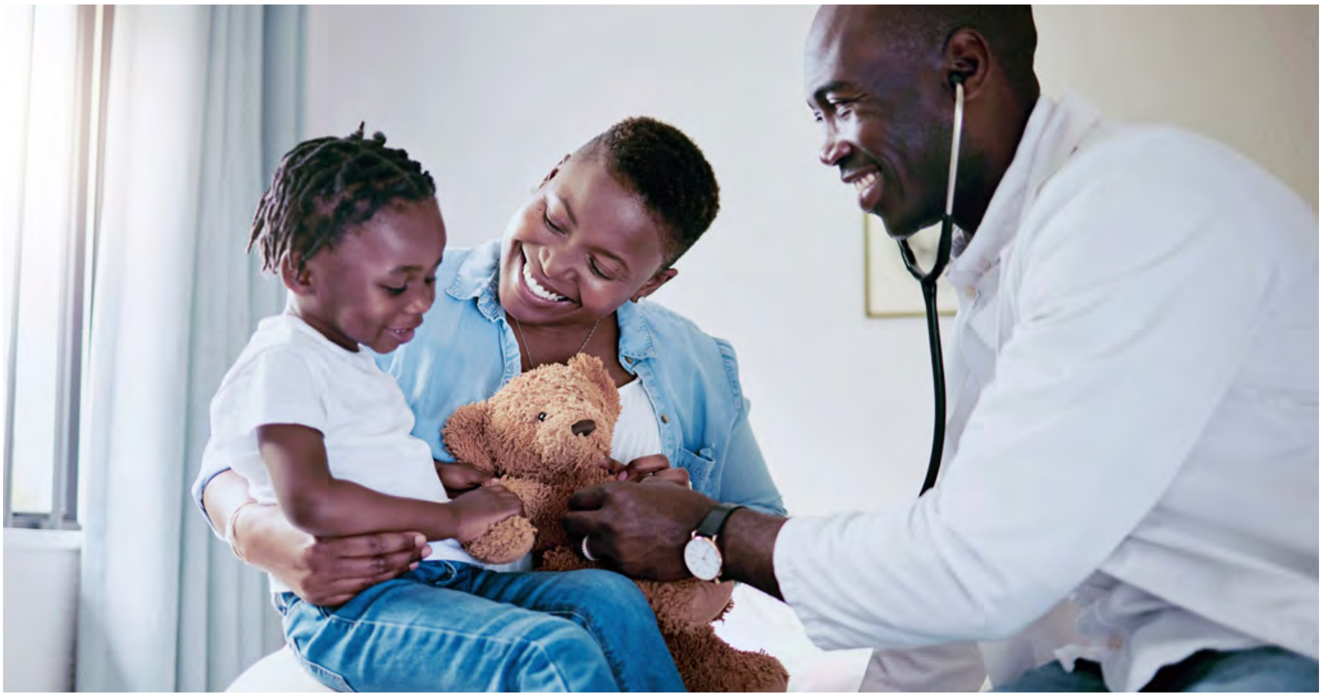
Introduction

The goal of palliative care in children is to improve the well-being of the patient and their family throughout the illness, as well as reduce physical, emotional and spiritual suffering.

Provision of palliative care begins at the point of diagnosis of a life threatening illness. It is important to follow the recommendations of the health team as you care for your child. The care may be provided in hospital or at home.

Who provides palliative care?

The entire health care team. This includes paediatricians and doctors in different specialties involved in the care of the child, nursing staff, psychologists, social workers, therapists, nutritionists, a medical team that specialises in palliative care and volunteers, among others.



Source of information for section 5: Excerpts from https://iris.paho.org/bitstream/handle/10665.2/58362/PAHONMHNVcvn1210040_eng.pdf?sequence=1&isAllowed=y

When should palliative care be provided?

Palliative care should be offered from the point of diagnosis as it provides greater benefits to the patient and their family. Palliative care is provided in conjunction with specific treatments for each disease, in order to support the patient and the family throughout the disease process.

What happens at the end of life?

At the end-of-life, palliative care may be provided in the hospital, in a special care facility (palliative care centre or hospice), or at the patient’s home, according to the preferences of the child or family. When the disease course is unfavourable, the palliative care team will continue to care for the patient during the end-of-life and will accompany the relatives during the period of mourning.

How does palliative care help my child?

It relieves your child’s pain and other physical symptoms.

- *It offers emotional, social, and spiritual support to the child and their family.*
- *It coordinates communication between the healthcare team and the family.*
- *It organises activities to improve the child’s quality of life.*
- *If needed, it allows planning and provision of end-of-life care.*
- *It provides support and care to the family while in mourning (bereavement care).*

There is always something that can be done to help your child feel better during the course of illness.

Source of information for section 5: Excerpts from https://iris.paho.org/bitstream/handle/10665.2/58362/PAHONMHNVcvn1210040_eng.pdf?sequence=1&isAllowed=y

AI generated image: Adobe Firefly https://firefly.adobe.com

Palliative care affirms life and recognizes that dying is a normal process, seeks neither to hasten nor postpone death, and this requires health professionals with high-level skills and expert care, individualised for each patient.

NOTE: The caregiver needs to be keen, take note and support children with pain. ***The following are some of the red flags to show that a child may be in pain;***

- *Irritability*
- *Unusual posture*
- *Reluctance to move*
- *Disturbed sleep pattern*
- *Unusual quietness*
- *Restlessness*
- *Sobbing*
- *Lethargy*
- *Screaming*
- *Aggressiveness*
- *Increased clinging*
- *Loss of appetite*
- *Whimpering*
- *Laying 'scared stiff'*

Source of information for section 5: Excerpts from https://iris.paho.org/bitstream/handle/10665.2/58362/PAHONMHNVcvn1210040_eng.pdf?sequence=1&isAllowed=y

06 **How to communicate**

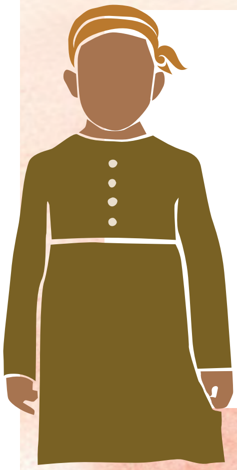
Introduction to the children's section

This part of the guidebook give useful information on how caregivers can communicate with children, have difficult conversations and address challenging topics.

In case of a life threatening or life limiting illness in your child, you may feel completely confused and paralyzed, and not know what to do. It is also likely that you will be overcome by anguish, sadness, and fear. It is essential that you seek the company of your loved ones so you can express and share these emotions.

> ***Sharing your emotions will help you achieve emotional balance, that will improve your communication with the sick child.***

Guidelines for interventions with a dying child:



1. Do not underestimate the child's capacity to understand
2. Create open communication, but do not force it
3. Provide creative outlets for anger, such as art
4. Follow the child's lead
5. Be honest with the child about impending death
6. Allow the child time to say good-byes
7. Permit the child to decide when he or she wants to share the pain of grief
8. Remember the child may choose to protect the parent (mutual pretense)
9. Help the dying child to live

Source: End of Life and Palliative Care by Jessica Hill and Aly Satisky as shared on https://www.slideshare.net/slideshow/end-of-life-palliative-care-246413796/246413796#42

Source of information for section 6: Fully adopted or adapted from (in no particular order) https://iris.paho.org/bitstream/handle/10665.2/58372/PAHONMHNVcvn6210040_eng.pdf?sequence=1&isAllowed=y | https://api.courageousparentsnetwork.org/app/uploads/2021/10/CPN-Silblings-Guide-4-2021.pdf | https://courageousparentsnetwork.org/blog/8-tips-to-communicate-effectively-and-compassionately-to-help-siblings-cope

The questions below address the major questions that you may have as the caregiver of a child with a serious / life-limiting illness;

A: DOES THE CHILD HAVE THE RIGHT TO RECEIVE INFORMATION?

YES. If the child is old enough to understand what is happening, then they have the right to be informed, just like the mother, father, and any other patient. The child is the lead player in this situation and needs to understand what is happening and what will be done to treat them. ***It is a myth to think that children do not understand.*** The child is experiencing symptoms they may never have had and are exposed to hospital conditions and procedures that make them realise this is not a common illness, like ones they have had before. Information about the situation and options always helps people of any age understand what is happening and stay calm.

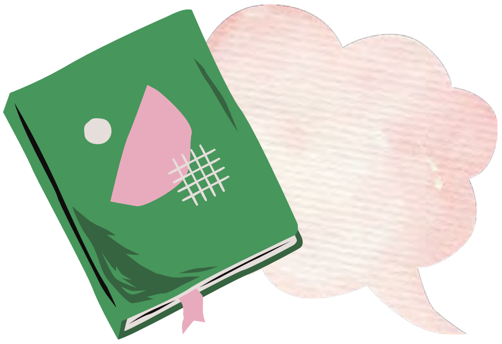
B: HOW SHOULD WE TALK TO THE CHILD ABOUT THEIR ILLNESS?

Honest and truthful conversation is always the basis of a trusting relationship. It is imperative that the child have these conversations with parents and health professionals. Lying will lead to blocked communication.

It is important to answer the questions that the child asks in the simplest and most empathic way possible. If their questions are not answered or are answered evasively, the child will sense that something is not right and that information is probably being concealed. ***This will further fuel their fears and lead to fantasies that may be more terrible than the actual situation.*** Another risk when information is hidden is that the child may find out from others who believe that the child has already been informed. This can happen if the child overhears a conversation between professionals.

A central issue will be the age of the child, because this will determine how you adjust your language and the way information is given to be sure the child understands what you are saying.

Stories, drawings, and other teaching materials can help make the information more concrete and understandable.



Source of information for section 6: Fully adopted or adapted from (in no particular order) https://iris.paho.org/bitstream/handle/10665.2/58372/PAHONMHNVcvn6210040_eng.pdf?sequence=1&isAllowed=y | https://api.courageousparentsnetwork.org/app/uploads/2021/10/CPN-Silblings-Guide-4-2021.pdf | https://courageousparentsnetwork.org/blog/8-tips-to-communicate-effectively-and-compassionately-to-help-siblings-cope

C: WHEN SHOULD WE TALK TO THE CHILD?

The best time to tell a child something is when they ask, as this indicates that they are concerned. It is important for the child to have the information needed to sort out their thoughts about the disease.

When explaining the comprehensive treatment plan to the child, be careful not to make it seem too long. Explain that treatment is based on stages and that it will be scheduled as it goes along. Make it easier to understand the concept of time by using calendars or similar materials.

D: WHO SHOULD RESPOND TO THE CHILD'S CONCERNS?

Mothers, fathers, or caregivers and health professionals should agree together on what information will be given to the child and who will be in charge of doing it, so as to avoid contradictions when talking with the patient. The child should be free to ask questions to whomever they feel comfortable with. Ideally, during a medical visit, the child should be given a chance to express how they feel before the parents do.

At the end of the visit, the child should be given time to talk with the doctor about any concerns. If treatment is being administered, the nurse should explain the procedures and what to expect.

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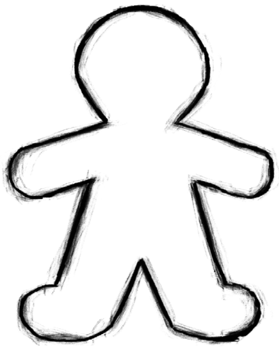
DAILY CHECK: This page helps the child relay their feelings without having to use too many words (especially useful if the child is very young or has very low energy).

How Are You Feeling Today?

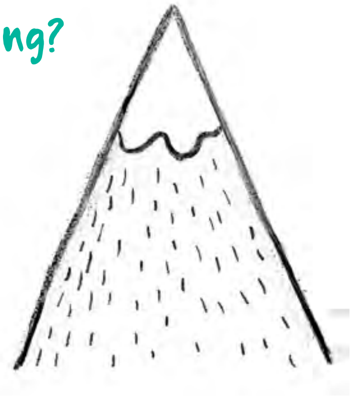
What colour is your feeling?

Where do you feel this colour in your body?



How BIG is your feeling?

Does it feel as BIG as a mountain?

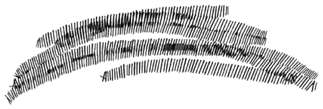


Or does it feel middle-sized … like the size of a chair?

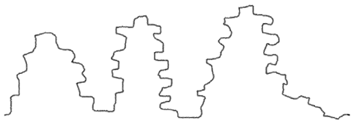
Or as small as a button?

If you could touch your feeling, how might it feel?

bumpy



prickly



wibbly wobbly

flat

swirly

soft

hard

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What else would you like to say about your feeling?

How to communicate with other family members including the child's siblings, and how to have difficult conversations*

AI generated image: Adobe Firefly https://firefly.adobe.com

Whenever the caregiver has to communicate with the family members of the sick child regarding the state of the illness, the general rules of communication should be used. It is best to ensure that the information being passed is;

1. **Clear.** Make sure that it's easy for whoever you are talking to to understand your meaning. This eliminates misunderstandings and assumptions that they may have on their own to understand what you're trying to say.
2. **Concise.** Stick to the point and keep it brief.
3. **Concrete.** Paint a clear picture of what you're telling them. Include all the necessary details and vivid facts.
4. **Correct.** Provide only information that is truthful, and when in doubt about the correctness of some information, consult with your child's health care team.
5. **Coherent.** Make sure that all points in your communication are connected and relevant to the main topic, and the tone and flow of the text is consistent.
6. **Complete.** Make sure that the listeners have everything they need to be informed and, if applicable, take action.
7. **Courteous.** Ensure that you communicate in a manner that is friendly, open and honest despite the pressure that comes with taking care of an ailing child.

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* Informaton built up from https://www.mindtools.com/a5xap8q/the-7-cs-of-communication

> ***The caregiver should explain to the sick child's siblings what the child's illness is, depending on their age and ability to understand, as well as the seriousness of the illness, and the reality and permanence of death.***

Infant and toddler siblings of a sick or dying child can feel loss through:

- *Absence of a parent or of a sibling due to the treatment or death of the sibling*
- *Interruption to routine caused by the treatment or death of a sibling*
- *Grief and stress of their parents or other family members*

These tips may help manage the feelings infant or toddler siblings of a sick or dying child may have:

- *Make time each day to hold, rock, and cuddle the sibling*
- *Keep the child on a schedule as much as possible*
- *Play a recording of parents reading a story or talking to the sibling in the parent's absence*

3 to 5-year-olds have responses that are shaped by the way they see the world:

- *They are magical thinkers and don't understand the difference between fantasy and reality. They may believe death is temporary or reversible*
- *They are ego-centric and may believe the death of a sibling is punishment for something they did*

Tips for helping 3 to 5-year-old siblings cope with their feelings about a sick or dying child:

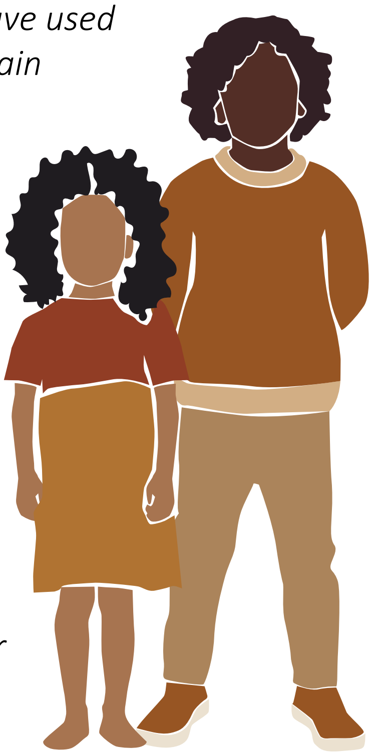
- *Use concrete language, such as "die," not euphemisms such as "sleep"*
- *At this age a child can understand "Your brother's body stopped working"; "Your sister stopped breathing"*
- *Make it clear to siblings that the death is not a consequence of something they did*

6 to 9-year-olds have a more evolved sense of dying:

- *They associate death with old age*
- *They may not understand that they or a sibling could die*
- *They know more about how the body works, so they may have specific questions about how someone dies. A sibling may think that a bruise on their own body indicates the same illness a brother or sister had*
- *They may associate death with frightening images from cartoons, such as ghosts and spirits*

Tips for helping 6 to 9-year-old siblings understand their feelings about a sick or dying child:

- *Use visual aids they can understand*
- *Child life specialists have used marshmallows to explain tumour growth or described leukaemia as a thickening of the blood*
- *Make specific references to organs like heart and lungs*
- *Make it clear that death is not like the images in cartoons*
- *Make it clear to siblings that what happened to a brother or sister doesn't happen to everyone*



10 to 12-year-olds understand the permanence of death:

- *They know that death is final and will happen to everyone including themselves*
- *They understand that their own death or the death of a sibling will cause sadness in others. A sick child at this age may say they have to hold on for their parents' sake*
- *They will respond more like adults with anger, sadness, and fear*
- *They will have increasingly more specific questions about the illness and about death*
- *They can find information on their own*

Tips for helping 10 to 12-year-old siblings of a sick or dying child:

- *Find opportunities for constructive venting of feelings, such as sibling groups at hospitals and art or play therapies*
- *Provide as much specific, factual information as possible*
- *Keep siblings in regular routines as much as possible. It may not seem like long, but professionals advise that children under age 12 not miss more than a week of school after a sibling has died. But they acknowledge that each child has unique needs*
- *After a death, make sure siblings still have a clear role in the family, but don't let them take on a parent's role*

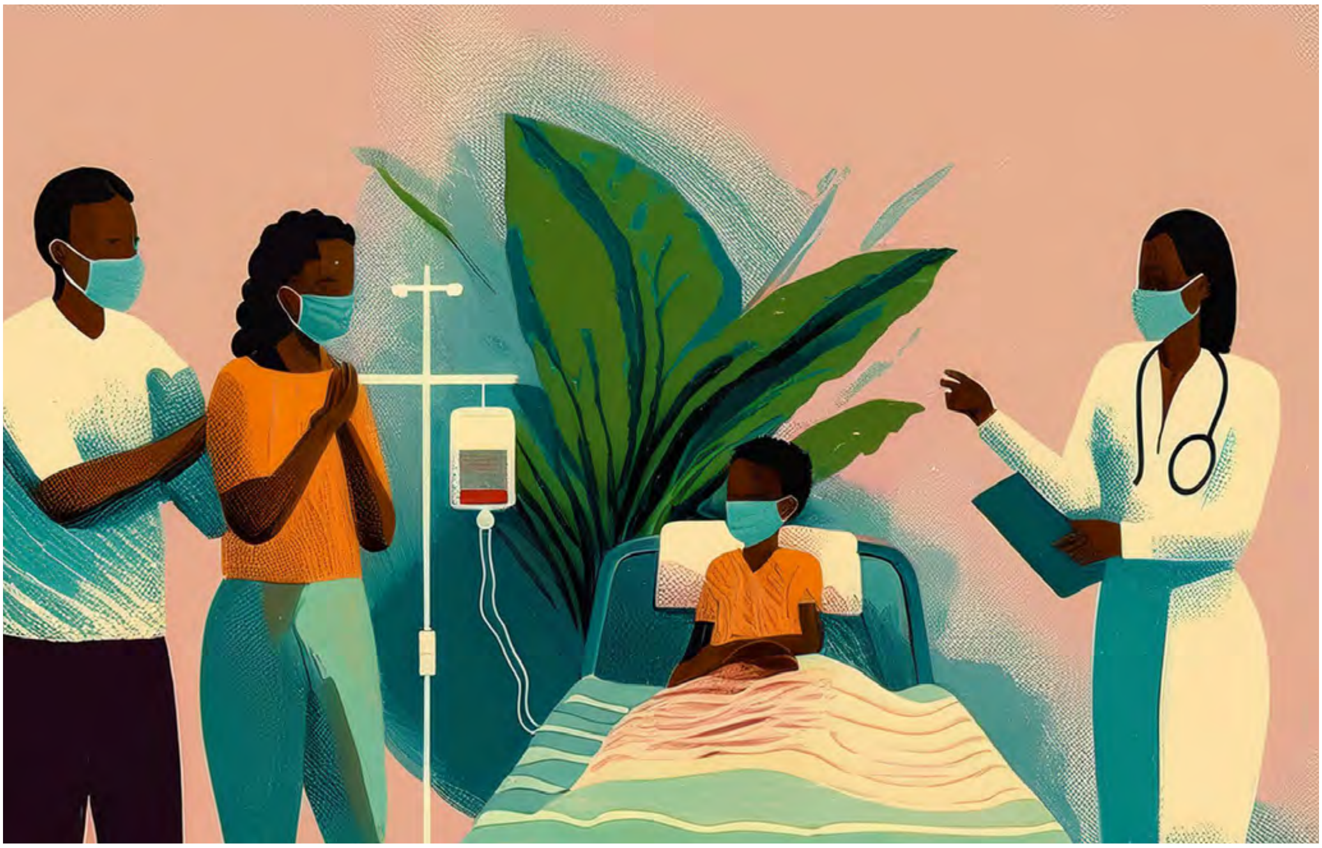
Teenagers understand death with a more personal and long-term view:

- *They may want to talk to their friends more than to their parents*
- *They understand more on their own, so adults are validating information rather than giving it*
- *They understand their lives in the context of others', so they will want to leave a legacy and plan for their own deaths*
- *They can find information on their own*

Tips for helping teenage siblings of a sick or dying child:

- *Let friends and boyfriends or girlfriends be involved. Palliative care teams encourage friends to visit and extend their support services to them*
- *Don't be hurt when teenagers seek the support of their friends more than their parents*
- *As teenagers' grief is more like that of adults, teenagers who lose a sibling may need more time off of school and regular activities*

> ***Children can be included in discussions about death and dying, but parents need not do it on their own. Palliative care professionals can help parents decide whether, when, and how to open this difficult conversation.***



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Source of information from https://www.hrrv.org/grief-support/childrens-understanding-death-developmental-guidelines/#:~:-text=10%20to%2012%20Years%20of%20Age&text=Intellectually%20understand%20it%20to%20be,and%20emotional%20aspect%20of%20death

07 **Symptoms and treatments**

Information on the kinds of symptoms that can present themselves and how to treat them

Your child may develop symptoms from the treatment they are receiving or from the disease itself. Ensuring the quality of life of children depends on optimal control of the symptoms that cause suffering.

When your child develops new symptoms or does not improve from existing symptoms, consult your health provider for management advice.

However, you may follow the steps on the next page to help relieve them when at home:

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Pain

Pain distresses the child and the caregiver. It could be mild, moderate or severe in nature.

Management includes both pharmacological and non-pharmacological approaches. Pain treatment should be applied according to the type of medication and the frequency indicated by the doctor.

- *It is important to keep a clear and precise record of doses of both normal and rescue medications so that your doctor can evaluate the effectiveness of treatment.*
- *Your doctor will prescribe the most appropriate medication to control your child's pain. If the pain is severe, you may need opioid medications to control it.*
- *The most commonly used medicine for moderate to severe pain in children is called morphine which is an opioid. Often, those receiving this medication sleep more than usual for the first three days. If the symptom persists, the doctor should be consulted again.*

Difficulty breathing

Difficult breathing or shortness of breath causes great distress to both the child and the family.

Therefore, it is important to remain calm so as not to exacerbate that sensation.

- *Have your child do breathing and relaxation exercises.*
- *Show them how to breathe in and out slowly.*
- *Find the most comfortable position for the child.*
- *Dress the child in loose, comfortable clothing.*
- *Make sure you have adequate ventilation in the room, by opening windows or using a fan.*
- *Help your child calm down if they become distressed at the feeling of being unable to breathe.*
- *If the difficulty persists, reach out to your palliative care provider.*

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Vomiting

Vomiting causes distress among patients and caregivers.

It may be due to treatment, illness progression, meals taken or other causes.

- *Avoid strong smells – e.g., perfumes.*
- *Remove leftover food swiftly.*
- *Offer small meals frequently if tolerated.*
- *Give the child fluids like oral rehydration solution (ORS).*
- *Consult your healthcare team if the vomiting episodes increase.*

Source of information for section 7: Pulled or adapted from https://iris.paho.org/bitstream/handle/10665.2/58368/PAHONMHN-Vcvn4210040_eng.pdf?sequence=1&isAllowed=y | AI generated icons: Adobe Firefly https://firefly.adobe.com

Lack of appetite

It is common for a child with advanced disease to have diminished appetite.

It is important to understand that the child may want to eat but cannot do so. Therefore, it is essential not to force them; it is better to ask what foods they want to eat. Remember that the child's decline is not due to lack of eating, but to the illness. Try to identify any causes that can be fixed. Stay calm if your child doesn't want to eat.

- *Make feeding schedules flexible to suit the child's preferences.*
- *Avoid strong odours.*
- *If possible, offer your child liquids more often.*
- *Prepare and offer foods your child likes, in small portions, but more frequently (several times a day).*
- *Clean your child's mouth before and after eating. If there is nausea or vomiting, follow your doctor's instructions (do not self-treat).*
- *If the child is unconscious, wipe their mouth and lubricate their lips.*

Constipation

Constipation is defined as the presence of dry, hard bowel movements or when one has a bowel movement less than three times a week.

It may be due to medicines your child is taking for pain, such as morphine. You may do the following to ease symptoms;

- *Increase the child's intake of foods with fiber (wheat bran, chia, fruits with skin on) and fluids depending on their condition.*
- *Give gentle abdominal massages.*
- *Consult the medical team if you feel distressed or cannot handle the child's situation. Tell the health care team if your child is constipated and keep track of their bathroom habits (frequency, amount, and appearance) and if your child has pain.*
- *Only give laxatives as directed by your doctor.*

Fever (high temperature)

The child is considered having a fever when his temperature is above or equal to 38ºC.

Use a thermometer to measure it. If your child has a fever;

- *Do not cover them up too much.*
- *Give liquids like water.*
- *Change the child's clothes or change the sheets if they are sweating excessively.*
- *Give the medicines prescribed by her doctor.*
- *Put warm damp clothes on your child or, if possible, bathe them in warm water for 10 minutes.*
- *Cover them up only if they have chills; This will make them feel better.*

> **If, despite these measures, they continue to have a high fever (above 39ºC), contact the health team.**

Note: Always consult the palliative care team before introducing new medications to the child. Self medication may be harmful.

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08 **Helpful sources of information**

It is important to connect with other caregivers going through similar experiences, to help you cope with any difficulties faced during this period as well as receive support.

Get in touch with us on 0722507219 if you are interested in joining, or starting a WhatsApp group for caregivers.

Online sources with helpful information:

1. THE CRIBSIDERS PODCAST- #62: Pediatric Palliative Care – Everything You Wanted to Know, But Were Too Afraid to Ask - September 7, 2022 | By Sam Masur
2. Testimonial (courageousparentsnetwork.org) - Numbers Family: Transplant for Severe Aplastic Anemia
3. Guide (courageousparentsnetwork.org) - A Parent's Guide to Self-Care
4. Guide (courageousparentsnetwork.org) - Communicating Effectively and Compassionately to Help Siblings Cope
5. Tips (courageousparentsnetwork.org) - 8 Tips to Communicate Effectively and Compassionately to Help Siblings Cope
6. Online Network - Courageous Parents Network
7. Printable poster to check in with the child(ren) in your care, to help them describe how they are feeling (e2epublishing)
8. Modules on Pediatric Palliative Care by the Pan American Health Organization as part of the World Health Organization
9. Guide - How to Explain Death to a Child, A Step-by-Step Guide (parents.com)
10. End of life & Palliative Care by Jessica Hill and Aly Satisky

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How to access palliative care services if not yet enrolled:

- *Talk to your health provider to link your child to a palliative care professional. Consent is required from you to receive these services.*
- *Refer to https://kehpca.org/pc-providers/ for a comprehensive list of palliative care centres in Kenya according to counties.*

Your health provider will give you information on the cost of services and extent of cover by insurance like NHIF or private insurance.

More information on children's palliative care may be accessed from www.kehpca.org or www.icpcn.org

Guidebook for caregivers of children receiving palliative care in Kenya

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