



Patient and family education and
admission guide for hospice care

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Contact number

You know what is best for your loved one. We're here to answer your questions, and we can usually help avoid an unwanted or unnecessary trip to the hospital. If you believe emergency assistance is required, please call 9-1-1 and then call us so that we can best support you.

We are available 24 hours a day, 7 days a week at the numbers listed below.

Office hours: 8 a.m. – 5 p.m., Monday – Friday

ON-CALL 24-HOUR SERVICE

Main phone number

Call service phone number

Concurrent care

In a pediatric hospice, when someone gets concurrent care, it means they can have both treatments that try to cure their illness and care that helps them feel comfortable. Some examples of these treatments are medicines, medical equipment, therapies and other ways to slow down or cure the disease.

Thanks to a rule in the Affordable Care Act, kids under 21 who qualify for Medicaid or CHIP and choose hospice care don't have to give up treatments for their illness. They can get both treatments that try to cure their illness and care that makes them more comfortable at the same time.



Value of pediatric home-based hospice.

Symptom management

Pain - Common symptoms include facial grimacing, loud crying, pointing/pulling/tugging at a particular part of the body, change in behavior (more clingy or more withdrawn, quiet, quicker to temper, etc.).

Do:

- Stay ahead of pain by giving pain medications on a schedule.
- Give a popsicle prior to medication administration. This can numb the tongue to decrease bitter taste.
- Mix medications with a snack or drink of preference such as chocolate syrup, chocolate milk, juice, apple sauce or pudding to mask taste. You can also use a medication dispensing pacifier for administration.
- Use non-medication treatments such as playing, singing, listening to music, swaying/rocking, soaking in a warm tub of water or using ice packs for swelling.

Avoid:

- Assuming children will express pain the same way as adults.
- Assuming that children are not in pain because they are not crying or verbalizing it.
- Fearing pain medication, stronger doses or the need for more frequent administration.
- Bouncing or abrupt motions.

Difficulty Breathing - A common symptom in children that can occur due to disease progression. Often characterized by feelings that the child "can't catch their breath," grunting, "belly breathing" or discoloration around the mouth and fingertips/toes.

Do:

- Provide oxygen as ordered by the care team.
- Administer medications as ordered by the care team.

- Utilize non-medication treatments such as repositioning the child with their head elevated, playing calming music, placing a cool cloth on their head or neck, turning on a fan to create a light breeze or opening a window to let cool air in.

Avoid:

- Overheating.
- Smoking around the child.
- Strong odors such as incense, candles, perfumes, etc.
- Overexertion. Your child's condition may not allow them to engage in physical activities or prolonged conversations as they once could.

Seizures - A common symptom that can occur depending on the disease progression. Your child may not show symptoms of seizure activity.

Do:

- Notify your hospice care team.
- Administer medications as ordered by the care team.
- Place your child on their side.
- Monitor the length of time the seizure activity occurs.

Avoid:

- Bright lights and loud noises.
- Placing any items in your child's mouth during a seizure event.

Nausea/Vomiting - A common symptom that can occur due to medical treatment, medications, motion, constipation, infection, pain, anxiety or fear.

Do:

- Allow rest periods and limit changes in position.
- Give small sips of an electrolyte drink, ginger ale or water.
- Provide popsicles, broth or gelatin in small amounts (clear liquids).

- Once liquids are tolerated, introduce toast, crackers or dry cereal.
- Utilize anti-nausea medications as ordered by the care team.

Avoid:

- Eating or drinking for 1-2 hours after a vomiting episode.
- Caffeinated beverages.
- Strong smelling foods.
- Lying flat for eating or drinking.

Constipation - Absent bowel movement for 3 days or more. Children are at an increased risk due to the usage of pain medication and decreased activity.

Do:

- Increase fluids and fiber products in their diet by making slight changes to their food intake such as adding more fruits and vegetables.
- Use a stool softener or laxative as ordered by the care team.
- Consult with your care team on the usage of home remedies such as olive oil, apples, prunes, kiwi, flaxseed, chia seeds or lemon juice, which may act as mild laxatives.
- Use gas relief medication as ordered by the care team that can help with painful gas.
- Massage the abdomen softly.

Avoid:

- Abrupt changes in diet.
- Changes in routine as much as possible.
- Cow's milk.

Diarrhea - Stools (bowel movements) are loose and watery. Your child may also need to go to the bathroom more often. In most cases, treatment includes replacing lost fluids. It can be a short-term event or a long-term event.

Do:

- Give the child lots of fluids. This helps replace the lost body fluids. If your child is dehydrated, be sure to:
 - Offer drinks called glucose-electrolyte solutions. These fluids have the right balance of water, sugar and salts. Some are available as popsicles.
 - Keep breastfeeding your baby. Breastfed babies often have less diarrhea.
 - Keep feeding your baby formula, if you were already doing so.

Avoid:

- Juice or soda. They may make diarrhea worse.
- Giving plain water to an infant less than 12 months of age unless otherwise directed by the care team.



Pediatric friendly care at home

The physical environment

Children who are confined to bed should be given input regarding where/how they sleep and how they interact with the day-to-day activity of the home. Allowing your child to have input in decision-making will ease boredom and feelings of isolation and helplessness. Below is a list of challenges you may encounter and some unique suggestions. Your hospice nurse can offer other suggestions based on your child's unique needs.

Challenge

Your child wants to sleep in their own bed, but their physical condition makes it impossible.

Suggestions

- Dress up the hospital bed with bright sheets and pillows they choose.
- Make a tent over the side rails.
- Allow them to show other family members how to use their bed's controls.
- Get their input on where the bed is placed.

Challenge

Your child is unable to go outside or into a different room.

Suggestions

- Hang mobiles, flags, kites or bright objects around the room. Provide a fan for air movement.
- Change the position of their bed in the room frequently.
- Place their bed near a window if possible.
- If unable to change the position of their bed, have your child reposition in the bed (i.e., sleep with their head at the foot of the bed). Make unusual events like this into "special events."
- If possible, roll your child's bed outside when the weather is nice.

Challenge

Your child has feelings of isolation, boredom and/or abandonment by friends.

Suggestions

- Encourage friends and family to visit and interact.
- Include your child in family-centered activities such as dinnertime, watching TV, birthday parties, etc. Have a backup setting such as a couch or reclining chair so that your child's position in the home can vary with family activities.
- Allow some privacy when friends visit. Adolescents and teenagers need private space to interact with one another.
- Encourage your child to do activities that can be done even bed bound such as board and card games, video games and computer games.

Challenge

They are experiencing feelings of helplessness.

Suggestions

- Allow your child to make as many decisions as possible (e.g., what and when to eat, what clothes to wear).
- Encourage your child to perform as much of their own personal care as possible.
- Put any items your child may need within reach so that they don't need to ask for help repeatedly.

Challenge

They are struggling between independence and dependence.

Suggestions

- Explain all treatments and the reasons for them.
- Provide physical assistance when necessary, but encourage your child to participate with repositioning, etc.
- Provide adequate protection for the bed linens so that any accidents or food spills are less upsetting.

Challenge

They have negative feelings toward their body image.

Suggestions

- Buy clothes that fit your child should they lose or gain weight due to their condition.
- Encourage your child to wear regular clothes during the day and pajamas at night.
- Provide privacy for your child when performing personal care.

Challenge

Your child is exhibiting attention-seeking behaviors.

Suggestions

- Children rely on consistent rules and find comfort and security in not being treated differently. Continue to set behavioral parameters whenever possible.



Child's coping with the concept of death

AGES	COMMON DEVELOPMENTAL CHARACTERISTICS	GRIEF REACTIONS	HELPFUL APPROACHES
2-5 years	<ul style="list-style-type: none"> Magical, fantastical thinking. Active fantasy life. Highly egocentric. Blame self for bad things. Not able to verbalize needs and fears. Need to repeat things. 	<ul style="list-style-type: none"> Confusion. Agitation at night, afraid to go to sleep. Able to appreciate a profound event has occurred, but may not understand permanence of death. Seem unaffected. Repeated questions. 	<ul style="list-style-type: none"> Simple, honest words. Reassurance about the future. Secure and loving environment. Drawing, reading, active play. Support play as form of expression. Include in funeral rituals.
5-8 years	<ul style="list-style-type: none"> Able to think concretely and logically. Language increases. Increased memory capacity, both long term and short term. Increased awareness of feelings and expectations of others. Peers are important. 	<ul style="list-style-type: none"> Want to understand death in a concrete way. Denial, anger, sorrow. Distress. Act as though nothing has happened. Want to be like peers. Repeated questions. Need regular physical activity. 	<ul style="list-style-type: none"> Look for confused thinking. Answer questions simply and honestly. Offer physical outlets. Reassurance about the future. Drawing, reading, playing together. Include in funeral rituals.

AGES	COMMON DEVELOPMENTAL CHARACTERISTICS	GRIEF REACTIONS	HELPFUL APPROACHES
8-12 years	<ul style="list-style-type: none"> Enjoy games and competing. Begin to have increased understanding of self and relationship to world. Increased propensity for language. Able to reason through situations using problem solving skills. 	<ul style="list-style-type: none"> Shock, denial, anxiety, distress. Try to cope. Understand finality of death. Curiosity about specifics of death and dying. Need regular physical activity. Want to be like peers. 	<ul style="list-style-type: none"> Answer questions directly and honestly. Reassurance about the future. Create times to talk about feelings and questions. Offer physical outlets. Reading. Include in funeral plans and rituals.
12-18 years	<ul style="list-style-type: none"> Need independence. Think abstractly. Puberty has begun by now. False sense of immortality. Peer group is important. Begin to have intimate relationships. 	<ul style="list-style-type: none"> Shock, anger, distress. Depressed or withdrawn. React similar to adult but have fewer coping mechanisms. Feel isolated, especially from peers. 	<ul style="list-style-type: none"> Allow and encourage expression of feelings. Encourage peer support. Support groups may be helpful. Maintain consistent environment. Include in funeral plans and rituals.

Guidelines for communicating with children

Communication with children and adolescents focuses on three key elements:

- **Inclusion** - Answer the child's questions honestly. Do not give the child the message that the question is inappropriate or wrong to ask. Children have a keen sensitivity to the emotional content in communication and can usually detect when information is withheld or untrue. Not answering the child's/adolescent's question honestly gives them the message that you do not think they can handle the information. This approach can diminish a child's sense of self-confidence.
- **Expression** - Children do not use talking as their major way of coping with or integrating painful information. Offer opportunities for the child/adolescent to absorb information and express feelings through activities, art, music, movement and/or other expressive options.
- **Support** - Understand children in the context of their own stage of development. Because adults are preoccupied with their own feelings and thoughts, they often assume they understand the question. Clarify a child's concerns by asking, "Could you tell me more about what you mean?" or, "Could you tell me more about what exactly you want to know?"

Understanding death for parents/ caregivers

The death of a child is unimaginable. It is important to note that no "levels" of loss exist. No two relationships are the same, so it is important not to compare one person's experience to another's. We should always remember that **Grief is Personal**. Elisabeth Kübler-Ross' five stages of grief include denial, anger, bargaining, depression and acceptance. However, grief does not follow a linear pattern; it manifests in countless ways, often simultaneously. Since grief is personal, remember to take care of yourself, your family and your significant other. If you need support, we have bereavement coordinators/counselors who can help you with anticipatory guidance as soon as you desire to include them in your and your family's journey.



Psychosocial elements

SOCIAL WORKER:

- Offers social services support in collaboration with the hospice team. The social worker and clinical team can provide community-specific resources that reinforce comfort and quality of life outside of the hospital setting.
- Provides concurrent care education utilizing traditional disease management options, symptom control and comfort at home.
- Serves as an added layer of care for you and your loved one.
- Assists with preparation for funeral arrangements.

SPIRITUAL SERVICES:

- Offer spiritual support in collaboration with the hospice team. The chaplain can help your child and family work through anxiety, fear, pain, frustration and confusion.
- Provide the opportunity to explore the meaning and sense of being connected with life and death.
- Serve as a companion to your child and family on the journey towards death.
- Assist with preparation for funeral arrangements.

VOLUNTEERS:

- Offer an added layer of support to your child and your family in collaboration with the hospice team.
- Are screened and trained in developmental needs, family dynamics, communication techniques and pain and symptom screening.
- Some service examples include providing a sense of presence, caregiver relief or serving as an outlet for sibling(s).

AIDES:

- Offer an added layer of support to your child and your family in collaboration with the hospice team.
- Provide in-home relief.

- Some service examples include cleaning, vacuuming, taking out the trash, picking up the mail and putting away groceries.

BEREAVEMENT COORDINATORS:

- Offer coping and grief support in collaboration with the hospice team. The bereavement coordinator helps your child and family prepare for the end-of-life journey and anticipate needs.
- Provide emotional, spiritual and psychosocial support.
- Support with addressing the stages in the grief process.
- Assist with preparation for funeral arrangements.

EXTENDED FAMILY SUPPORT:

Siblings

- A child's illness affects the entire family. Give special attention to the siblings' emotions. Encourage siblings to find someone they trust to whom they can express their feelings. Siblings can be encouraged to express their feelings through coloring, painting, journaling, play-acting, etc.
- **Communicating the concept of death with children**
All children, especially a sibling, will be affected in some way by a death in the family. Their response to this loss will vary based on factors such as:
 - The nature of the child's illness and circumstances of their death.
 - The developmental and chronological ages of the child who died and the surviving children.
 - The relationship between the deceased child and surviving children (unresolved feelings of guilt and resentment over the attention the child received may still exist).
- It is not uncommon for surviving siblings to feel they must fill the void in the family created by their brother or sister's death. Parents should help them understand the uniqueness of each individual.

Classmates/teachers

Families often wonder how to interact with schools when their child has a life-threatening illness. Schools may not have encountered this situation before and may be uncertain how to help students and their families. The Compassus team, along with the school liaison, can help families and school professionals work together to maintain a high quality of life for the ailing student. The student's medical condition and hospice goals will be reviewed, guidelines provided and additional programming suggested that may be helpful.

Families have a right to expect that the school adapt to and offer educational services. In some cases, the school will offer home tutoring for students to continue their studies. However, many students want to continue to go to school even though their illness may require that their school day and activities be modified.

When students who are ill are able to and want to continue to go to school, school professionals can work with parents to make decisions about how many hours of school a child can attend, how medications or illness affect the student's day, what activities are possible and what staff support is required to assist with this plan. Teachers, nurses, principals and sometimes social workers or guidance counselors are involved.

One of the school's concerns will be the social fabric of the school community and how your child will interact with peers in the classroom. The Compassus team is available to help teachers and students understand your child's illness and what they may be experiencing. Worries and fears that other students may have can be addressed and support can be given on how to have healthy communication. Classmates may want to offer assistance. Do not hesitate to offer ideas to classmates' families about what is helpful to you such as preparing meals, doing yard work or taking siblings out for an activity. Request from the school or teacher that one parent from the class is designated to coordinate these services.

Community

Relationship to your community

You and your family will continue to interact with outside organizations such as your religious community or your child's school. You have the right to choose what information to share with others. You may want to base this on what is most comfortable for you and what will be helpful to your grieving children. In general, it is helpful for the daycare, school and religious community to know what has happened in order to be sensitive to your needs.

Older children's guidance counselors can explore whether plans for post-graduation should be altered following a loss with your family. Compassus liaison staff can contact the school and assist in developing a plan to help your child and other children at the school. Our staff can provide information about the grieving process and normal reactions in children. You are not responsible for other people's responses.



Frequently Asked Questions

What is the role of the hospice team?

Compassus focuses on managing pain and other symptoms to improve your child's quality of life.

Will my child need to stop chemotherapy, radiation or other curative treatments to take advantage of pediatric hospice services?

No. Curative treatments and care can be provided concurrently. Compassus collaborates with the child's doctor or specialist to provide an extra layer of support.

Can we keep my child's doctor?

Yes. The team will collaborate with your child's pediatrician or specialist on a customized plan of care.

Are services covered by insurance?

Most services are covered by private insurance or Medicaid.

The Compassus team can meet with families to discuss financial options if necessary.

Additional Resources

National Hospice and Palliative Care Organization

www.nhpco.org/pediatrics

Caring Information

www.caringinfo.org/resources

Courageous Parents Network

www.courageousparentsnetwork.org

Funeral Services

www.funeralservicefoundation.org

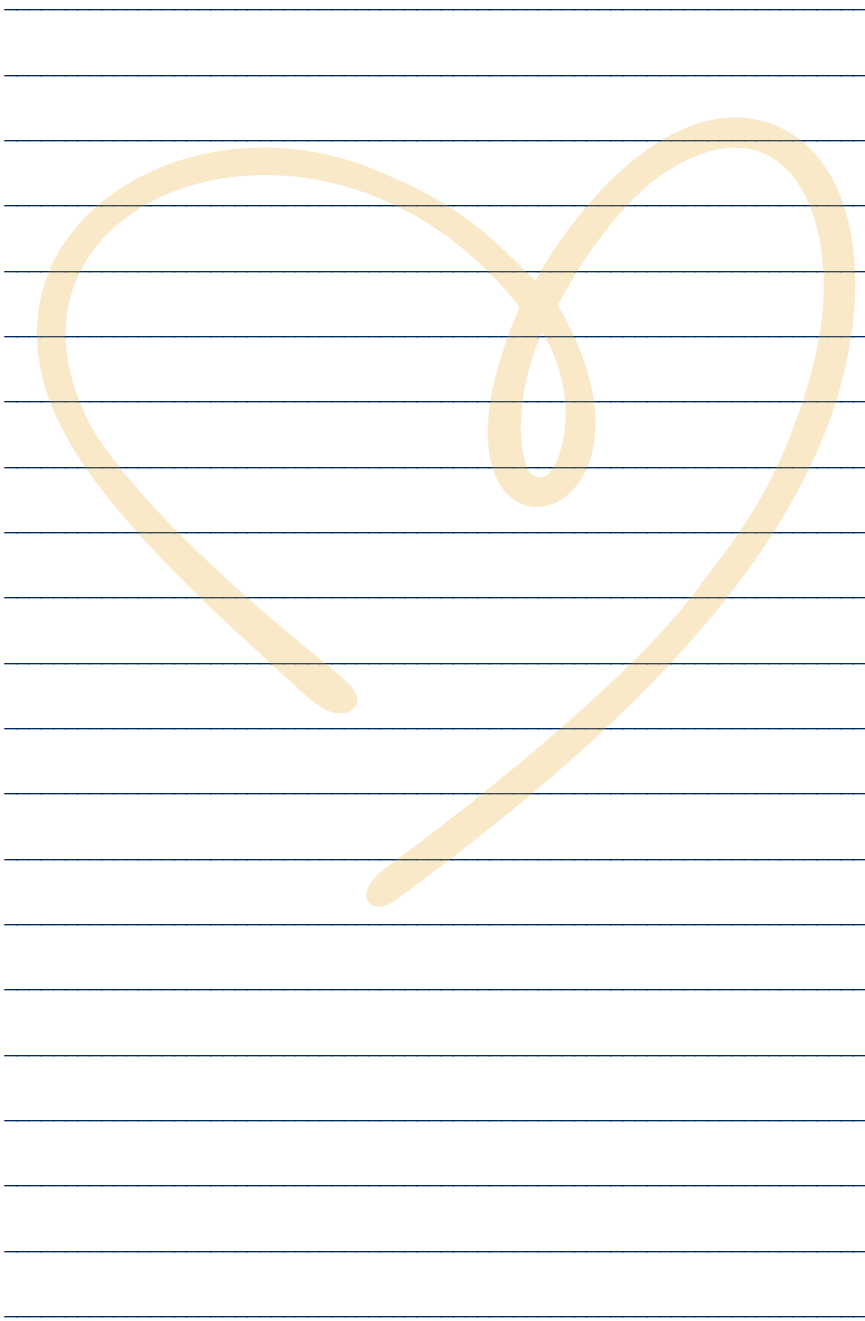
The Compassionate Friends: Supporting Family after a Child Dies

www.compassionatefriends.org

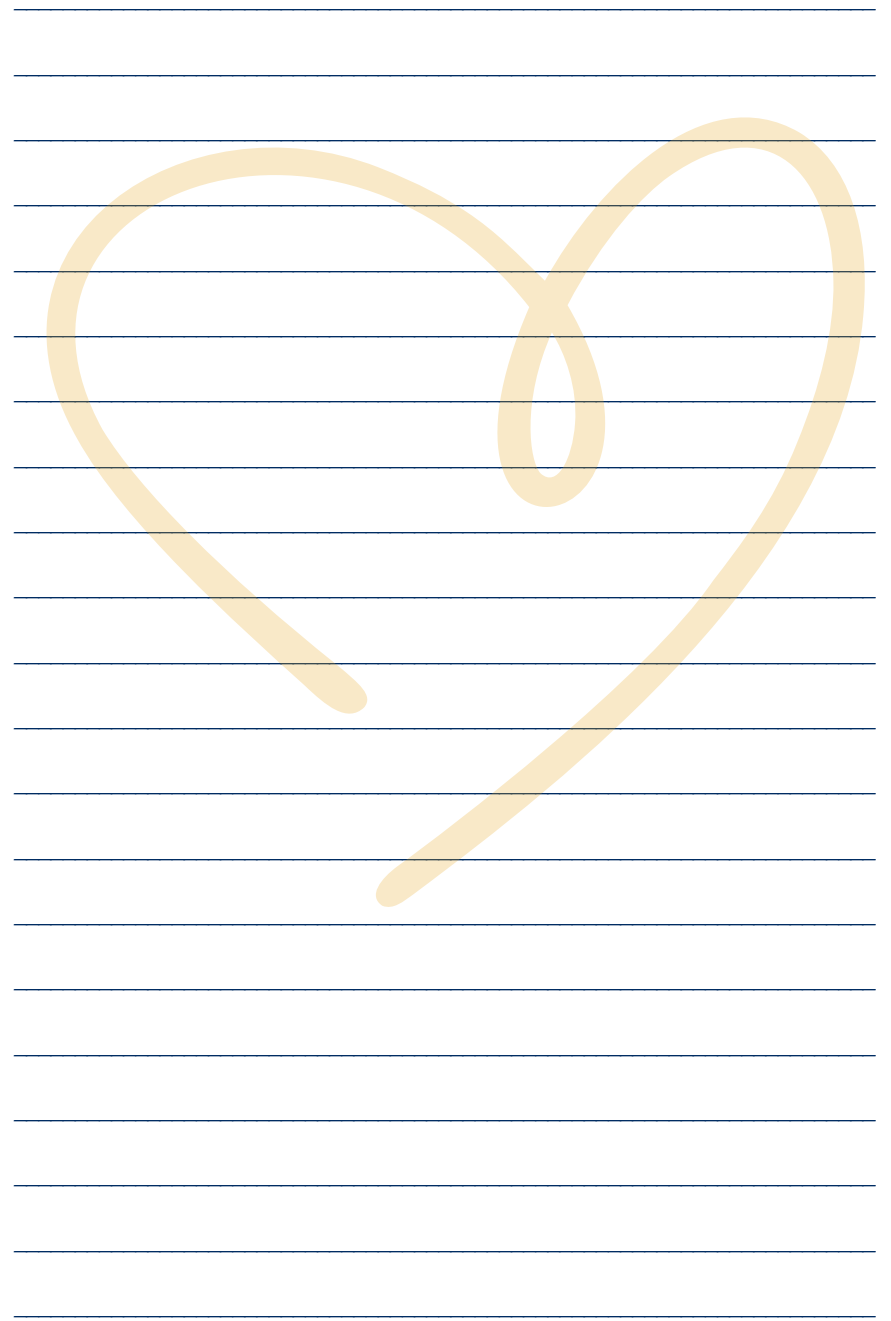
Available reading booklets for children coping with the dying process:

- *I Will Always Love You* by Melissa Lyons.
- *When Someone Dies* by Andrea Dorn.
- *The Memory Box* by Joanna Rowland.
- *Gone but Never Forgotten* by Pamela Rae Hughey.

Notes



Notes



Compassus offers a full continuum of integrated home-based care services.

Home Health
Infusion
Palliative
Hospice

compassus.com



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