



What Do We Do Now?

WHEN A CHILD IS SERIOUSLY ILL



Gentle Shepherd

HOSPICE

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Introduction

When a child is seriously ill, it can seem like your world has been shattered. There may come a time when hard decisions need to be made about your child's care. You might feel powerless, scared, or alone. You might ask, "What do we do now?"

This booklet will answer some of the questions you may have. It gives practical advice about talking with and caring for a seriously ill child. It also gives information on what to expect.

You are not alone. The care team is here for you. We will guide you every step of the way and prepare you for what is ahead. We will help you bring comfort, love, and support to your child and your family during this difficult time.

*"While we try to teach our children
all about life, our children teach us
what life is all about."*

— Angela Schwandt

Talking with the Care Team

We are your care team. The care team can include your child's doctor, nurses, home care aides, social workers, pharmacists, therapists, chaplains, etc. A care team guides patients and families through the stages of an illness.

Your child, you, and your family are central members of the team. We need to know your family's goals. Try to get comfortable sharing your thoughts and feelings with us.

It is important for the care team and family to talk to each other openly and honestly. Good communication can lead to a feeling of trust. This can help guide tough decisions in the future.

What you can do:

- Write down your family's goals, wishes, values, routines, and traditions. Share these with the care team.
- Learn the names and roles of the care team members who are working closely with your child.
- Understand what the care team is doing and why. Ask about what you don't understand. If appropriate, let your child know what's happening. We can help with this, if you wish.
- Speak up when things do not seem to be working. Be realistic in what you expect.
- It's natural to feel confused or unsure about what to do next. Let the care team know about any concerns you have. We can help you sort out what is important at any given time.

From Cure to Comfort

Even when the best medical care is given, sometimes a cure is just not possible. Finding out there is no cure for a child is heartbreaking. A family dealing with this news is faced with hard decisions.

Some families may wish to keep curative care at this point. Curative care focuses on a cure for the disease. This includes treatments like chemotherapy, antibiotics, or dialysis. These treatments may cause physical discomfort or other side effects.

Some may choose to focus on comfort. Comfort care centers on quality of life for the patient and family. Medicines and therapies control pain and other signs of the disease.

Other families may want curative care with comfort care. This is a personal choice made by your child and family. No decision is the wrong decision.

What you can do:

- Based on your child's age, involve him or her as much as possible in decision making. Older children and teens will want to be involved in choosing their own care.
- Learn as much as you can about all treatment options. Talk to the care team. Do your own research.
- Consider what you and your child want regarding treatments. Which options are you both comfortable with?
- Work with your child to make a list of pros and cons for curative care and comfort care. Review this list with the care team or doctor.

Hope with Hospice

At some point, you may have to consider hospice care. Deciding to shift from cure to comfort is one of the hardest decisions a family will make. But it's an important choice to explore.

Hospice is a special kind of palliative (or comfort) care. It is care that focuses on the unique physical, social, emotional, and spiritual needs of the patient. Hospice care also helps loved ones cope with the illness.

Pediatric hospice care focuses on the special needs of children. Hospice patients usually must stop curative care. But many times hospices will have more care options for children. Some allow curative care alongside hospice care.

What you can do:

- Share your thoughts with a professional. Speak with your child's doctor or call hospice. See what options are available.
- Talk to family, friends, or spiritual counselors about hospice.
- Write down your child's and your family's questions, plans, hopes, and fears. Share these with the people you talk to.
- Try to keep hope. There are still many things to hope for. Hope for a good day. Hope for the relief of your child's pain.

*“Everything that is done in the world
is done by hope.”*

— Martin Luther

Talking with Your Child

Many adults avoid talking to children about death. They may not be sure what to say. Some think they are protecting children by not talking about it. It's a hard conversation, but it's an important one to have.

Kids know what's going on. Even very young children pick up on the moods of the adults around them. Sick children notice changes in routines. They feel the changes in their bodies. Avoiding talking to a sick child can cause feelings of mistrust.

Talk openly and honestly with your child. This helps keep him or her from feeling lonely, helpless, or guilty. This is a time when your support is needed most. This is a time to connect with your child, share thoughts, and express love.

What you can do:

- Ask the care team to help if you're not sure how to start. They are experts in having these tough conversations.
- Let your child talk about all of his or her thoughts and fears. It's important that the child expresses all of his or her emotions.
- Let yourself show all of your emotions. This gives your child permission to express his or her feelings. Talk to your child about how you feel. Don't be afraid to cry in front of the child.
- Answer questions honestly. Children will have a lot of questions. They want the truth. There will be questions you can't answer. Be honest about not knowing. Offer to explore these questions with your child.
- Ask open-ended questions. "How do you feel about that?" is better than "Does that make you sad?"
- Follow your child's cues. Don't make the child talk if he or she doesn't want to. If your child doesn't want to talk, leave the door open to talk later.

Age Level

How you talk with your child will depend on his or her age. Young children communicate very differently than teens. Keep in mind, many children understand a lot more than adults think they do.

Clear language is important. Use simple, direct words. Using the words “death” and “dying,” is better than saying “passing away” or “going to sleep.” Look for books or other visual aids to help with understanding. Ask the care team for suggestions.

Young children may need play or art to work through tough subjects. Older children and teens may respond to books, other media, or more direct talks.

Age 0 - 2 years: This age group does not understand death. Their biggest fear is loss of relationships and routines.

Age 2 - 6 years: This age group thinks death is temporary. They may think death is a kind of punishment. They may feel guilt or need to vent other feelings.

Age 6 - 11 years: This age group can use reason. They understand that death is final. They need to be able to talk about their feelings.

Age 11 years or older: Older children and teens understand that death is final. They may have their own thoughts about death. Sick teens struggle most with their changing body image and the need to be independent.

What you can do:

- Contact the care team if you're not sure how to talk to your child. Look for resources online or counselors who work with children and teens.
- Let your child know that you will always be there for love and support. Every child, no matter what age, needs to hear this.

The Other Children

Siblings often are left out when there is a sick child to care for. Some families try to protect siblings by keeping them out of the loop. Some simply have little time or energy to care for siblings.

Be aware of the needs of the other children in the family. If siblings are not included, they may imagine things that are worse than they really are. They, too, may feel lonely, helpless, or guilty. Siblings may also feel jealous that the sick child is getting so much attention.

It's just as important to talk with siblings as it is with the sick child. Again, base talks on age level. Keep siblings involved if possible. They need special attention at this time, too.

What you can do:

- Siblings may be afraid to share their feelings. They may be ashamed for feeling angry or jealous. Or they may not want to add to your stress. Seek them out. Ask about their feelings often.
- Try to have one-on-one time with siblings. Ask family members or friends to help plan activities just for the siblings.
- Don't try to protect siblings from the child's illness. If appropriate, teach siblings about the illness. Let them know what to expect.
- Keep siblings involved in the everyday life of the sick child. Have siblings help with the child's care. Ask them to help with simple tasks, like serving meals.
- Let the sick child and siblings spend quality time together. This can be as simple as watching TV or playing games.
- Encourage siblings to draw pictures, make cards, or write letters to the sick child.

Quality of Life

You may feel powerless in the face of your child's illness. But there are ways to take back control. There are steps you can take to improve your child's quality of life. Quality of life is how a person feels day to day. It includes emotional, social, physical, and spiritual wellness. It's important at every stage of life.

Be aware that your child's needs will change over time. Pay close attention to the child. Adjust activities, schedules, and care tasks as needed. Contact the care team any time you need extra support.

Emotional needs

Coping with a serious illness can be a challenge for people at any age. Children feel many of the same feelings at the end of life as adults. Love, affection, and feeling safe are all important to a child's emotional needs.

What you can do:

- Learn to be a good listener. Never interrupt the child. Be non-judgmental, caring, and reassuring. Accept if your child doesn't want to talk. If you need to talk but the child does not, talk to family or a trusted friend.
- Continue to set limits to keep your child's behavior from getting out of control. Even though the child is sick, he or she still needs guidance from a parent.
- Always treat your child with dignity and respect. Give older children as much independence and control as possible. Loss of control and physical changes may cause depression.
- Have pets or a stuffed animal nearby to cuddle. This can be comforting even for older children.

Social needs

Children are always learning about the world around them and how to interact with others. This is part of a child's social development. It is closely linked to the emotional support from family. This development should continue, even through a serious illness.

What you can do:

- Keep routines as normal as possible. For example, try to have dinner at the same time you normally would. Routines help the whole family.
- If your child is in school, continue school work for as long as possible. Meet with the school staff to talk about options.
- Give your child time to be a kid. Take a break from treatments and caregiving to do something fun. Look at photos, watch movies, listen to music, or play games.
- If your child is not at home, decorate his or her room with familiar items. Let the child choose pictures, posters, or other meaningful things to place around the room.
- Encourage visits by friends and family, within limits. Too many visitors can be tiring for the child and the family.
- Set up phone or video calls for family and friends living far away. Let older children stay connected to friends by text and social networking.
- Create memories as a family. Take photos, make videos, write letters, or draw pictures together.
- Find a group that grants wishes to seriously ill children. A big trip, a letter from a celebrity, or a shopping spree can make special memories. Check with the care team if you're not sure where to start.

Physical needs

A sick child has many physical needs. This includes things like day-to-day care and managing pain. The care team will see to many of these needs. We may also train you on some caregiving tasks.

Pain is one of the most feared symptoms of illness. The care team will work with you and your child to provide comfort with medicines and therapies. Be aware that pain can change from day to day — even hour to hour. We may adjust the care plan as needed.

What you can do:

- Talk openly with the care team about your child's needs. Share what you know and observe about the child. You know your child best.
- Ask the care team to tell you what is being done to control your child's pain. Update the child, if appropriate.
- Give medications on schedule. Avoid skipping doses. Always follow the care team's orders, even if it doesn't seem like your child needs the medicine. If you are not sure, ask the care team.
- Consult the care team before giving over-the-counter medicines or supplements.
- Gently rub the child's back or watch funny videos. Try small things to take your child's mind off the pain.
- Ask the care team about other ways to relieve pain. We may suggest hot/cold pads, simple exercises, or other therapies (such as massage, acupuncture, art, music, or pet therapy).
- Create a calm, comfortable space for your child. Keep the room clean and free of clutter. Adjust the room temperature for the child. Provide extra blankets and pillows, if needed.

Spiritual needs

Being spiritual does not always mean being religious. Spirituality can mean believing in a higher power. It can mean feeling like a part of something bigger than yourself. Some families have strong ties to a religious belief. Other families find spirituality in the wonders of life.

Most children look to their parents and families for spiritual guidance. Practicing spirituality with your child can help your family find meaning during this difficult time. For many, seeking meaning and asking why are a big part of this experience.

What you can do:

- Let the care team know what your family's spiritual beliefs are. The family's spiritual beliefs will help guide the care plan.
- Contact a trusted religious or spiritual counselor. He or she can be a great source of comfort.
- Practice rituals with your child to connect spiritually. Follow rituals of your faith, or create new rituals for your family.
- Though it may be hard, take time to give thanks. Try to focus on small things like having a quiet moment or just being able to spend time together.
- Be aware that some questions may not have answers. You may turn away from your faith or change beliefs. This is a normal reaction. You are allowed to feel this way.
- Call us to see if there is a chaplain on staff. Most care team members focus on the physical needs of the child. The chaplain is there to give you extra emotional support. Support is based on your family's beliefs.

What to Expect

There will be noticeable physical changes as the illness progresses. Some of the symptoms may be upsetting. Our hope is that knowing what to expect will help ease the way for you, your child, and your family.

We provide some tips that may help. However, each situation is unique. This section is only a general guide. Please contact the care team if you notice any changes. We may have special advice for your child.

Changes in breathing

Breathing patterns may change near the end of life. Breathing may start and stop, or become very slow and shallow. Some patients can be given oxygen to help with comfort. The care team will tell you what can be done.

What you can do:

- Let the care team know if there are changes in breathing. We may give oxygen or medication if it is needed.
- Try raising the head of the bed to make breathing easier.
- If the child can swallow, offer ice chips, freezer pops, or small sips of water.
- Breathing through the mouth is common in later stages. The mouth can get dry. Use a wet swab or sponge to keep the lips and tongue moist.

Changes in eating

The body doesn't digest food in the same way at the end of life. This can be one of the harder changes to accept because many families connect food with caring. As the body slows down, there is no need for food. This does not mean the child is hungry or being starved.

What you can do:

- Do not force foods. Follow the child's wishes for meals.
- Giving small bites of favorite foods can bring comfort.
- Liquids may be better than solid foods.
- Contact the care team if the child has trouble swallowing. We may suggest thicker liquids, like milkshakes or smoothies.

Changes in toileting

There may be loss of bowel and bladder control. This could be caused by the illness, medication, or weakened muscles. This can be embarrassing for older children. Always keep the child clean and dry.

What you can do:

- Check the child often to be sure he or she is dry and comfortable. Give older children as much privacy as possible during personal care.
- Diapers and bed pads may help.
- The care team may suggest placing a catheter, or a tube, into the bladder. This helps keep the skin dry.

Changes in behavior

Changes in behavior can happen because of the illness or medications. These may include depression, anxiety, or confusion. These changes are a normal part of the dying process. We can show you how to best support the child at this time.

What you can do:

- Contact the care team. We will make sure the right amount of medicine is being given. We'll give other support as needed.
- Always use a calm, soothing tone of voice. Reassure the child of your love and support. Let the child know you are there and will keep him or her safe.
- If you can, gently reorient the child if he or she is confused. Remind the child who you are, where you are, and what you're doing. If you can't easily reorient the child, just let the child express what he or she is feeling or seeing.

Changes in energy level

The child may start to withdraw. There will be less of a need to talk. Touch and silence take on more meaning. Just being present for the child is the most valuable gift you can give. Feeling tired and weak is normal at this stage. More and more time may be spent asleep.

What you can do:

- Keep the room quiet and peaceful. Limit visitors and reduce noise. Turn the TV, phones, or music down or off.
- Keep talking softly to the child, even if the child isn't awake. Always speak to the child as if he or she can hear you.
- There may be moments of alertness. Use this time to express your love and say what you need to say.

Saying Goodbye

Some families don't know how to say goodbye. Some are afraid to say it. They worry about telling the child it's okay to let go. There is no right or wrong way to say goodbye. Each family will do this in its own way. If you wish, invite close friends and other family members to visit. This is a special time for you, the child, and loved ones.

What you can do:

- Give the child permission to let go when he or she is ready. Assure the child that you and the family will be okay. Sometimes this is important for the child to hear.
- Consider having a close family member, friend, or spiritual counselor there to support you. The care team may also have a chaplain available for spiritual support.
- Hold the child, or hold the child's hands, if you can. Let yourself cry. Use this time to give thanks, say "I'm sorry," or say whatever is in your heart.
- It's okay if you don't get to say everything you want to say. The child knows how you feel, even if you don't say it out loud.

"If ever there's a tomorrow when we're not together, there's something you must always remember...even if we're apart, I'll always be with you."

— *Christopher Robin*, Pooh's Grand Adventure

When the Time Comes

Nobody knows exactly when death will happen. Even if you know what to expect, it can still be a huge shock. You may want to have family and friends close by for support.

More changes will happen at this late stage. Breathing and heartbeat weaken more. Skin color and body temperature may change. There is no longer a need to eat. Bladder and bowel function slows. Most of the time may be spent asleep. The care team can let you know if there are other signs to expect.

What you can do:

- It may be helpful to prepare ahead for this moment. Consider having close family members or friends there to support siblings or to help make phone calls.
- Some families take this time to honor the child. Gather family and loved ones who are present. Cry together, light a candle, play special music, or share a ritual from your family's spiritual beliefs.
- If the care team is not already there, contact us. We will support you and your family. We will confirm the death, arrange for equipment to be removed, and give you guidance on how to dispose of any leftover medicine.
- If you wish, we can also help bathe the child or contact the funeral home. Some families want the funeral home to be called right away. Others choose to wait.
- The funeral home will help you make plans for services, if you wish. Some families choose to have a formal service. Some have an informal "celebration of life" or other ritual. There are no right or wrong choices. Follow your heart. Involve the whole family as you explore options.

The Family's Needs

A lot of time and energy goes into the care of a seriously ill child. It's easy to lose focus on your own needs and the needs of the rest of the family. Be sure to take time to care for yourself during caregiving and after your loss.

Caring for yourself during this time is not selfish. It is a necessity. Taking care of yourself will help give you the strength to go on. It's important to stay healthy for yourself and for your family.

What you can do:

- Reach out for help. Assign tasks to others. Get help from family, friends, and the community.
- Consider joining a support group. Connecting with others who have had a similar experience may ease feelings of being alone. Hearing other people's stories can give you hope for the future. Contact the care team for suggestions. There are support groups for all ages.
- Take a break from caregiving. Ask the care team about respite care. Get away from the bedside for a couple of hours to recharge. Take this time to do things for yourself. Spend time with your other children, have coffee with a friend, watch a movie, or just have quiet time alone.
- Find healthy outlets for your emotions. Talk with a close friend or family member, start a journal, listen to music, or create artwork. Cry whenever you need to. Tears help relieve stress, lower blood pressure, and promote healing.
- Get rest, eat well, and exercise. Avoid alcohol and drug abuse, overeating, or other negative habits. Try meditation or yoga.
- Be gentle with yourself. Take life one moment, one step at a time. It may seem impossible right now, but you *can* get through this. Remember that we are here for you.



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