



PATIENT AND
CAREGIVER
RESOURCE GUIDE



Advanced Pediatric Care™

*A Guide for Families Caring for
Children with a Serious Illness*



NPHI National Partnership
for Healthcare and
Hospice Innovation



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I. Introduction

This guide was made by experts who care for children with serious illnesses. These experts have been providing extra support to children and their families since the 1990s. Many parents do not know about this kind of care, but it can help children stay comfortable at home and avoid trips to the hospital.

What We Do

Our goal is to help parents give their child the best life possible. That might mean trying to cure the illness, helping the child live longer, or simply making them more comfortable. You are never alone. A caring team is here to support you and your family every step of the way.

What Is Palliative Care?

Palliative care is all about helping your child feel better and live as well as possible. It can ease pain, reduce symptoms, and improve quality of life. Palliative care works with your child's other doctors and treatments.

What Is Concurrent Hospice Care?

Since 2010, children with serious illnesses can get hospice care while still receiving treatments that might help their condition. "Hospice" may sound scary, but for kids it means more help. It can help families manage symptoms, keep your child comfortable at home, and give you 24/7 access to help and advice.

Who We Support.

How long your family works with us depends on what you need, what you want, and what your doctors recommend. Our goal is to be with your family for as long as you need us, offering guidance and care every step of the way.

We also work closely with your child's other doctors to help your child live as well as possible and to help your family during your time together, however long that is.

Note: When this guide says, "your child," it means children of all ages, from birth through young adulthood.

This guide is here to help you and your child understand and work with your care team to make the best choices for your family.

II. What Is Pediatric Palliative and Pediatric Hospice Care

Pediatric Palliative Care

- Helps children with serious illnesses feel better.
- Focuses on comfort and quality of life.
- Can happen anytime during illness, even while getting treatments.
- Helps with:
 - Pain and symptom management.
 - Emotional and social support for your family.
 - Keeping doctors and care team on the same page.
 - Talking openly about care choices.

Because services are not available everywhere, check with your care team to see if pediatric palliative care is offered in your area.

Pediatric Hospice Care

- For children whose illness may lead to death within about six months if the disease continues without treatment.
- Concurrent care lets children get treatments to help them live longer or cure the disease AND get comfort care at the same time.
 - Can start earlier in the illness and last weeks, months, or years.
 - Provides support for complex needs at home or in facilities.
- Helps provide support for anticipatory grief through bereavement care.

Both Palliative & Hospice Care

- Focus on your child's and family's wishes.
- Support family caregivers.
- Manage pain and other symptoms.

- Support emotional and spiritual needs.
- Help families make choices and reach goals.
- Create a care plan to treat the illness, dialysis, or mechanical ventilation.

Four Levels of Hospice Care

These are different hospice care options that your care team will discuss with you when necessary.

- **Routine Home Care** – regular care at home
- **Continuous Home Care** – extra help during crises at home
- **General Inpatient Care** – short-term, intensive care in a hospital or facility
- **Respite Care** – short-term care that gives families a break from caring for a child with serious illness. It can take place at home, in a hospice center, or another safe setting, and trained staff care for your child while parents or caregivers rest and recharge. This support can help families manage stress and take care of their own needs. Because it is not available everywhere, check with your hospice team to see if this service is offered in your area.

These services can happen in different places, depending on what your child needs. The way they are paid can also be different, based on your insurance (like Medicare, Medicaid, or private insurance). The different types of hospice care may not be available everywhere and can depend on the hospice and where you live.

Insurance & Access

- Under the Affordable Care Act, children under 21 with Medicaid or CHIP have access to concurrent care in all states.
- Many commercial and private insurances also cover concurrent hospice services.
- Availability may vary by location and hospice provider.
- Depending on your insurance, where you live, and your child's doctor, your child may need to qualify for adult hospice care after they turn 21.

Going Back to the Hospital

- Your child may need hospital care sometimes – that is okay.
- Always keep your hospice care team updated on changes.

III. Your Care Team

Someone from the hospice team is available by phone 24/7.

Your care team visits when needed, but they do not stay all the time or replace a full-time caregiver. They also work with your child's other doctors who manage equipment, medicines, supplies, and treatments.





Depending on where you live, your care team may also include **Expressive and Integrative Therapists*** who can help your child feel better, without using medicine. An example is a Child Life Specialist. They can:

- Help support families in making a care plan.
- Help with relaxation and reduce stress.
- Support you and your child's body, mind, and spirit.
- Increase comfort for your child.
- Offer art, music, pet visitation, or massage therapy if they think it will help.
- Help families have age-appropriate talks with children about a child with a serious illness.

*These services may be different from one hospice to another.



Your Care Team

Use this chart to write down the names of your child's care team. Remember to call your hospice's 24-hour phone number if you have any questions or notice changes in your child.

Care Team Members	Care Team Member Name
24-Hour Access Phone Number:	
Core Care Team	
RN Case Manager	
Social Worker	
CNA/Qualified Hospice Aide	
Chaplain	
Physician	
Volunteer	
Other Care Team Members	
Administrator	
Clinical Manager	
Hospital	
Other	

Working Together

The care team works closely with other doctors, nurses, and caregivers to make sure your child gets the best care. They coordinate with providers who manage different medical equipment, medicines, supplies, and treatments to provide the best care to your child and family. This teamwork helps your child stay safe and comfortable.

Hospice care can provide many of the medical supplies, durable medical equipment, and medications needed for comfort at home. This helps families worry less about getting these items and focus more on being together.

IV. Communicating with Your Child

Sometimes adults may not talk to children about serious illnesses because they are afraid it will be too scary. They worry it might make things worse, or they do not know what to say. But children often understand more than adults think. And right now, they need your support the most.

Shared Decision Making

Talking about serious illnesses with children, teens, and young adults can be hard. These talks are often put off or skipped. But many children think about these issues and want to help make choices about their care, what they want their family and friends to know, and what is important to them. Letting them make decisions about their care can help them feel more in control and give them a stronger sense of purpose. Here are some ways to help:

- Learn as much as you can about the illness.
- Let them decide when and how to talk about it.
- Give plenty of time to talk and do not rush.
- Start with simple facts and easy words.
- Be open and honest.
- Let them know their feelings are okay.
- It is okay if you do not know all the answers.
- Adjust questions to your child's age and feelings (see Appendix C).
- Ask questions to understand what your child knows, how they feel, and what they want. For example, you could say, "How do you feel about that?" (see Appendix B).
- Be gentle, listen carefully, and don't give too much information at once.
- Let your child know it's okay to feel scared, sad, or unsure. Their feelings matter.
- Answer honestly in a way your child can understand and provide comfort.
- Talk with your care team to help get and to have these conversations with your child.

These conversations help children share feelings, understand what's happening, and express their wishes. Below are some helpful tools that can help children write down and share their wishes as part of advance care planning. Your hospice care team or social worker can guide you with these and other resources.



When There Are Siblings in the Family

Serious illness affects the whole family, including siblings. Here's how to help them:

- **Be Honest and Clear:** Use real words like “cancer” or “diabetes.” Explain changes (“Your sister’s medicine makes her sleepy”), and if you don’t know an answer, say so.
- **Let Them Ask Questions:** Listen, be patient, and check that they understand. Kids may ask the same question more than once.
- **Keep Routines and Offer Reassurance:** Maintain normal activities, show siblings they are loved, and explain that adults’ stress is not their fault.
- **Let Them Be Involved:** Allow visits, talking, and simple caregiving tasks.
- **Shows Emotions Honestly:** It is okay for adults to be upset, as long as it does not put pressure on the child. This helps kids know it’s normal to have strong feelings.

Talking About Death

- Children react to death in different ways.
- Let them talk, ask questions, and share their feelings.
- Reassure them that it is not their fault.
- Use simple, clear words.
- Share your beliefs about death and let them share their ideas.

More Communication Help

- Talking with Your Child About Illness and Care (see Appendix B)
- Communicating at Every Developmental Level (see Appendix C)
- Helping Young Children Understand a Sibling’s Illness (see Appendix D)
- When Death Is Near: What You Might See (see Appendix E)

V. Improving Your Child's Quality of Life

Your care team and the nurse case manager can help you learn how to track your child's symptoms and make them feel better.

Physical Needs/Managing Pain

Signs That Your Child May Be in Pain

- Tight muscles: stiff legs, clenched fists, shaking, jerking, kicking, or thrashing
- Body position: arched back, stiff posture, sudden movements
- Facial changes: frowning, clenched jaw, wide or blank eyes
- Sounds: crying, moaning, grunting, gasping
- Behavior: quiet, less active, pulling away
- Skin: pale, red, or sweaty
- Overall: Hard to comfort, nothing seems to help

Ways to Measure Pain

Use the FLACC (Face, Legs, Activity, Cry, and Consolability) scale to help check pain in young children who cannot say how much it hurts. Each part is scored from 0-2, and the scores are added up. The total score goes from 0-10. A higher score means more pain.

FLACC Scale	0	1	2
1 Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested.	Frequent to constant frown, clenched jaw, quivering chin.
2 Legs	Normal position or relaxed.	Uneasy, restless, tense.	Kicking, or legs drawn up.
3 Activity	Lying quietly, normal position, moves easily.	Squirming, shifting back and forth, tense.	Arched, rigid or jerking.
4 Cry	No crying (awake or asleep).	Moans or whimpers, occasional complaints.	Crying steadily, screams or sobs, frequent complaints.
5 Consolability	Content, relaxed.	Reassured by occasional touching, hugging or being talked to, distractible.	Difficult to console or comfort.

Wong-Baker FACES® Pain Rating Scale: Use this scale to help check pain in children ages 3 and up to show how much pain they are feeling.



0

No Hurt



2

Hurts Little Bit



4

Hurts Little More



6

Hurts Even More



8

Hurts Whole Lot



10

Hurts Worst

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurts a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

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Ways to Control Pain

- **Mild to Moderate Pain:** Non-opioid medicine, such as acetaminophen (like Children's Tylenol) or ibuprofen (like Children's Advil or Motrin), may work well.
 - These are over the counter but always tell your care team if your child is taking them.
 - Other medicines, like ones for anxiety or depression, may also help with pain, swelling, or muscle tightness.
- **Moderate to Severe Pain:** For stronger pain, your child may be prescribed an opioid medicine like morphine or oxycodone.
- **Comfort Kit:** You may get a kit from your care team. This kit has special medicines to help treat symptoms quickly at home.

What to Expect with Pain Medicine

The care team, under the doctor's guidance, may order opioid pain medicine for your child's symptoms. They may change these medicines over time as needed.

- Doses are usually based on weight and are carefully set for your child's needs. The care team watches for side effects and can make changes quickly if needed. It may take a few days to find the right dose.
- Your child may feel sleepy at first. Some nausea or vomiting may happen but usually goes away.
- Constipation is common. Your care team may also give medicine to help with this. Keep track of your child's bowel movements and let the care team know about any changes.
- Stay on schedule and give the medicine on time, even at night. This keeps the pain from coming back. If the pain comes back before the next dose, tell the care team.
- Many parents worry about opioids because of things they hear in the media or personal beliefs, like concerns about sleepiness, addiction, or speeding up death. In hospice care, opioids are used safely and carefully to treat pain or help with breathing. Addiction happens when someone takes medicine to feel high, but in hospice care, the medicine is used only to manage real symptoms. When pain is controlled, your child can rest better, spend time with family, and enjoy activities they like.
- Sometimes the body gets used to the medicine and needs more. This is normal and different from addiction. The care team will adjust the dose as needed to keep them comfortable.
- Medicine for pain can help many children, but it may not take all the pain away. The goal is to make symptoms happen less often and feel less strong. Some children feel better with two or even three medicines. Others still have pain, even with several medicines. The best plan may be to use two regular medicines and to have a way to treat pain when it breaks through.

Breakthrough Pain

Pain may happen even when your child is already taking regular medicine for ongoing pain. It is like a pain flare-up that breaks through the usual treatment.

These are guidelines to help you and the care team decide if the medicine should be increased or changed when these breakthroughs happen. You and the care team know your child best and can choose how to use this information. If their symptoms do not get better, it is okay to ask for extra help.

← How Good Is Good Enough? Finding the Balance →			
Pain	Frequent episodes	Try to keep severe pain episodes that need stronger medicine (not Tylenol or Ibuprofen) and improve within 1 to 2 hours to 3 or fewer per week.	Fewer pain episodes
Wakefulness	Poor sleep	Look for a balance between being awake during the day and getting good sleep at night.	Sleepy during the day

My Child's Medicine(s):

Make sure you give your child the right amount of medicine (see Appendix A).

Anxiety/Agitation

Prescribed medicine name, if any:

Constipation

Prescribed medicine name, if any:

Fatigue

Prescribed medicine name, if any:

Nausea/Vomiting

Prescribed medicine name, if any:

Pain

Prescribed medicine name, if any:

Seizures

Prescribed medicine name, if any:

Shortness of Breath

Prescribed medicine name, if any:

Managing Other Physical Symptoms

For treatment ideas that do not use medicine, ask your care team about the best options that fit your child's needs. Use this chart to write down what works best for your child.

Symptom	At-Home Treatments
Constipation	<ul style="list-style-type: none"> • Give lots of water, juice, or Jell-O. • Add fruit and vegetables if they can eat them. • Try dried fruit or whole grains (bran cereal, whole wheat bread). • Short walks may help. • Tell your care team if constipation keeps happening; they may suggest stool softeners or other treatments.
Ideas for Your Child	<p>.....</p> <p>.....</p>
Diarrhea	<ul style="list-style-type: none"> • Keep track of how often they poop. • Give plenty of fluids but skip juice and fruit; they can make diarrhea worse. • Keep their skin clean and dry. • Ask your care team about medicine if needed.
Ideas for Your Child	<p>.....</p> <p>.....</p>
Dizziness	<ul style="list-style-type: none"> • Have them rest when they feel dizzy, sleepy, or very tired. • Help them stand up slowly (sit up first, let their feet hang for a minute, then stand). • Stay close if they feel dizzy when walking. • For older kids, ask about a safety belt to help with walking.
Ideas for Your Child	<p>.....</p> <p>.....</p>

Eating

- Be gentle and encouraging. Do not force them to eat.
- Keep meals calm and quiet.
- Let them choose food. Small meals are fine.
- Offer small meals or snacks often.
- Use high-calorie foods (ice cream, pudding, shakes).
- Blend or chop food if chewing or swallowing is hard.
- Ask about food supplements.
- Keep their mouth clean between meals.
- Use straws, droppers, or syringes for drinks if they cannot hold a cup.
- If using a feeding tube, ask if you should adjust the amount.
- Tell your care team if their eating changes a lot.
- Give pain medicine on time.

Ideas for Your Child

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Incontinence

- Ask your care team about diapers or a bedpan.
- A catheter may help drain pee (it is a small tube that drains pee into a bag).
- Change wet items fast. Keep skin clean and dry.
- Be kind; they may feel embarrassed.

Ideas for Your Child

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Managing Energy (Fatigue)

- Plan things when they have the most energy.
- Skip things that are not important.
- Let others help with chores, meals, or spend time with them.
- Rest when needed and let them rest too.
- They are not lazy; they just feel tired.

Ideas for Your Child

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Mouth Dryness and Sores

- Brush teeth gently with a soft toothbrush and a small amount of toothpaste.
- Avoid brushing too far back.
- If they cannot swallow, your care team will show you how to keep their mouth clean and moist.
- Avoid spicy or sour foods.
- Give soft food and drinks often.
- Offer sips of water.
- Give sips of water with dry foods to help with swallowing.
- Rinse mouth often (no-alcohol mouthwash).

Ideas for Your Child

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Nausea and Vomiting

- Keep the room quiet and calm.
- Avoid strong smells.
- Give clear drinks (broth, water, clear soda).
- Try dry snacks like crackers.
- Peppermint or ginger (tea or soda) may help.
- Offer small meals often.
- Skip spicy, greasy, or sour food.
- Ask about nausea medicines.

Ideas for Your Child

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Pain

(see page 15 for more information about pain medicine)

- Keep the room quiet and calm.
- Play soft music or read to them.
- Let them have favorite toys, books, or videos.
- Visitors can help distract from pain.
- Cuddle, rock, massage, or give warm baths.
- Change positions often.
- Try weighted blankets or vibratory mats and pillows.
- Things like essential oils or Reiki may help.
- For tummy pain, check for constipation.
- If they have a feeding tube, vent it if needed.
- Tell your care team if pain gets worse.

Ideas for Your Child

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Seizures

- Stay calm. Stay with them.
- Move things away so they do not get hurt.
- Put something soft under their head.
- Gently roll them onto their side.
- Loosen tight clothes.
- Time the seizure.
- Give rescue medicine if told to.
- Call 911 if the seizure lasts more than 5 minutes.
- Do not put anything in their mouth.
- Do not try to stop their movements.
- Wait until they are awake before giving food or drink.

Ideas for Your Child

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Shortness of Breath

- Stay calm.
- Help them breathe slowly in and out (try pursed-lip breathing: breathe in through the nose, then breathe out slowly through the lips like you are blowing a kiss or whistling).
- Sit them up and then lean forward with arms resting on a table or pillows.
- Use a fan to keep air moving near them.
- Raise the head of the bed or use pillows to help them sit up.
- Ask about oxygen if needed.

Ideas for Your Child

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Sores

- Change their position often (every 2 hours in the day and every 4 hours at night if they can handle it. If it hurts to move, do it 30-45 minutes after pain medicine).
- Wash with mild soap.
- Use lotion around (not on) sore spots.
- Check heels, elbows, and hips for redness or sores.
- Ask about soft pads or a special mattress.

Ideas for Your Child

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Emotional Needs

Children with serious illnesses may feel scared, worried or sad. This is normal. Sometimes they do not want to talk about how they feel because they want to protect their families. Here are some ways to help:

- Talk to your care team if their behavior changes.
- Show your own feelings. It is okay to cry sometimes. This can help them feel safe to share their feelings too.
- Give them art supplies, toys, and time to play. These can help them express emotions.
- Try to be thankful, even when it is hard. Being thankful can help you and your child feel stronger inside.
- It is important to have tough conversations, with help from the care team, so your child has a safe way to share their hopes, wishes, fears, and worries.



Learning and Social Needs

Children still need to learn and spend time with others, even when they are sick. Here are some ways to help:

- Be kind and respectful to them.
- Try to keep their daily routine as normal as possible.
- If they can go to school, it is good for them to keep going.
- Keep setting rules and limits like you always have.
- Watch for big changes in how they act around others. This might mean they need help from a counselor or therapist.
- Join a support group to meet other families going through similar things.
- Read their favorite books with them.
- Play their favorite music.
- Plan fun activities between treatments or care.

Spiritual Needs

Many families ask big questions like “Why is this happening?” and try to find meaning during hard times. Here are some ways to help:

- Share your family’s beliefs with your care team.
- Understand that some questions may not have clear answers.
- Talk with a spiritual care counselor or chaplain.
- If your family is part of a faith group, try to join services in person or online. Or ask if someone can visit you at home.
- Practice new or old family traditions.
- Take time each day to be quiet, think, and be thankful.

VI. Parent/Caregiver Self Care

Parents and caregivers have a lot to do. One of the most important jobs is taking care of your own body and mind. Focusing on these areas will help you stay strong, be there for your child, and enjoy time together.

Take Care of Your Health

- Rest when you can. Your child may need more help over time, so it's important to recharge.
- Eat healthy. Even if your child isn't eating much, you still need food to stay strong. Keep easy, healthy snacks nearby.
- Move your body. A short walk or light exercise can help you feel better and sleep better.
- Sleep matters. For better sleep, follow a bedtime routine and go to bed around the same time each night. Avoid big meals, caffeine, and screens before bed. Keep your room quiet, dark, and comfortable.
- Do not use a lot of alcohol or drugs to deal with your child's situation.

Let Others Help

- Take breaks. It's not selfish as it helps you stay strong.
- Ask for or say "yes" to help. Let friends, family, or volunteers give you a hand.
- Support each other. Talk with your partner or other adults about how to work as a team and handle disagreements.
- Respect different coping styles. Some people cry; others stay quiet. Everyone handles stress differently.
- Keep doing things you enjoy when you can. Stay connected to friends and activities.
- Ask for what you need. People may not know unless you tell them.
- Know when to seek outside help. If things get too hard, talk to a counselor. Your care team can help you find one.
- Even strong people need support. Do not miss out by trying to do it all alone.
- Talk to your care team if taking care of your child feels too hard.

Your Emotional Well-Being

Caring for a seriously ill child is very hard. It can bring up many emotions for you and your family. Everyone may feel things at different times and in different ways, and that's okay. These feelings are normal. You are going through a lot. Get more help on how to deal with difficult feelings (see Appendix F).

Courageous
Parents Network



VII. Financial Concerns

Insurance, like Medicaid, or other benefit programs may help pay some or all of the costs of supportive care. Talk with your insurance company and the social worker on your care team to learn about your options. The social worker can guide you through Medicaid or CHIP (Children's Health Insurance Program) coverage, connect you with financial help from the hospital or community, explain the costs of things like medical supplies and equipment, and share resources such as state programs that may give extra support.

Understanding Insurance and State Benefits

Work with your social worker to understand your specific benefits. Here are some possible options:

- **Health Insurance.** Check with your insurance company to learn what your plan covers for pediatric palliative and hospice care. Ask about things like deductibles, co-payments, and any costs not included. Your care team will help you verify your benefits.
- **Medicaid and CHIP.** In all states, Medicaid and CHIP cover pediatric hospice care and offer “Pediatric Concurrent Care,” which lets your child receive both treatment for their illness and hospice care at the same time.
- **State Waivers.** Some states have special programs, like “Care at Home,” that help cover services for children with disabilities. These waivers may pay for care at home instead of requiring a hospital stay.
- **TRICARE.** TRICARE gives concurrent care to patients under 26 with full coverage.
- **Commercial Insurance.** Many, but not all, commercial insurances (examples: Blue Cross, Aetna, etc.) allow access to concurrent care.

Note: Because coverage can be different depending on the state and the type of plan, families should talk with their insurance provider to find out what services are included. Most hospice agencies can also help families check benefits and coverage when they begin the referral process.

VIII. Appendices

Appendix A: How to Measure Medicine

Use these tips to measure and give your child's medicine the right way.

ALWAYS

Use the metric system (ml or mg).

Use an oral syringe for small amounts of liquid medicine.

Hold measuring cups at eye level to get the right amount.

If the label says ml (milliliters), use a tool marked in ml.

If the label says mg (milligrams), use a tool marked in mg.

Ask your care team if you are ever unsure how to measure.

NEVER

Never use kitchen spoons as they are not accurate.

Never use a cup that doesn't show how much it holds.

Never switch droppers between different medicines.

Never measure ml using a tool marked in mg.

Never measure mg using a tool marked in ml.

Never leave air bubbles in the syringe as they change the dose.

Note: Milligrams (mg) and Milliliters (ml) are NOT the same!

Measuring Tips

A chart of measuring cups and measuring spoons.



10cc=10ml
20cc=20ml
30cc=30ml

Tip: use an oral syringe for amounts less than 5mls



Reminder: 1cc=1ml
A cubic centimeter is the same as a milliliter

mg. ≠ ml.

A mg is NOT the same as a ml !!!

Tip: always read the label carefully to be sure you are measuring the right thing.



This 15ml cup contains 20mg of medication.



This 15ml cup contains 40mg of medication.

YOU CAN'T TELL THE DIFFERENCE BY LOOKING

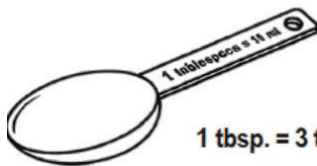


1 tsp. = 5ml.



Tip: To be accurate, use the correct measuring tool. Ask your pharmacist. Some liquid medicines have special measuring tools.

Tip: Don't use household teaspoons. They are not accurate!



1 tbsp. = 3 tsp.



3 tsp. = 15ml.



25 mL



Tip: When measuring liquids, hold the cup at eye level!

Appendix B: Talking with Your Child About Illness and Care

These questions can help you understand what your child knows, how they feel, and what they want. They also give your child a chance to share feelings and wishes in a safe, supportive way.

Question	Why Ask It	Example Follow-Up Question
Do you know why you're feeling sick?	To see what your child knows about their illness	What do you think is making you feel unwell?
What have the doctors told you about your illness?	To check how much your child understands	Do you remember what the doctors said might happen next?
How do you feel about your treatments?	To understand your child's feelings	Is there anything about the treatment that worries you?
What do you think the doctors are trying to do with the treatments and medicines?	To see if your child understands treatment goals	Do you understand that the doctors want to help you feel better and make the sickness go away?
If you could choose your care, what would you like?	To learn your child's wishes	Would you like to try new medicines, or keep things the same?
Sometimes we have to make hard decisions about what kind of care we want. Would you like to talk about what you want if you feel very sick?	To open up a conversation about difficult decisions	Would you like to be in the hospital or stay at home when you're very sick?
Do you know what happens when people get very sick and can't get better?	To check understanding of death	What do you think happens when someone's body stops working?
What do you think it means when we say someone has passed away?	To see how your child understands death	Do you think that means the person is sleeping or something else?

How do you feel about the idea that we might not be able to fix your sickness?	To see how your child feels about not being cured	It's okay to feel sad or scared. How can we help you feel better right now?
What are the things that are most important to you right now?	To understand your child's priorities	Is there something special you'd like to do with your family, or something that makes you feel safe and happy?
If you feel too sick to do certain things, like go outside or play, how would you like to spend your time?	To see how your child wants to spend time if their condition gets worse	Would you like to read, talk to family, or listen to music or stories?
How would you like people to remember you?	To talk about legacy and memory-making	Would you like to make a drawing or write something for your family?
If you feel scared or worried, what would help you feel better?	To understand what brings comfort	Would you like to talk, hold hands, or do something relaxing?
Do you know that even though your body is very sick, the people who love you will always be with you?	To reassure your child about love and support	Even if your body is sick, you are still loved and cared for. Does that make you feel better?
Do you know what you want to happen if you feel really tired and need to rest?	To see how your child wants care during hard times	Would you like to rest in a quiet room, or have people around you?

Appendix C: Communicating at Every Developmental Level

Use this chart to help talk with your child in a way that fits their typical age. Your care team can also help you learn how to best support your child.

Age	Things to Know	What You Can Do
Infants and Toddlers (Birth – 2 Years)	<ul style="list-style-type: none"> • Do not understand what serious illness or treatment means • Might become extra clingy or harder to calm down • Feel stressed when their body changes, their routine changes, or when people around them seem upset • Feel most scared when routines or caregivers change 	<ul style="list-style-type: none"> • Give lots of love and cuddles • Try to keep a simple daily routine • Talk openly with other adults to help keep things calm around your child • Help your child get to know the care team so they see familiar, friendly faces
Preschool (3 – 5 Years)	<ul style="list-style-type: none"> • Might know about serious illness from someone they know or a pet • May believe their thoughts or actions caused the illness or can fix it • May ask the same question many times to try and figure things out • Might go back to younger behaviors like thumb sucking, tantrums, or bedwetting 	<ul style="list-style-type: none"> • Be honest and open when talking about illness • Use simple words and stop often to make sure they understand • Give the same answer each time • Give extra love and comfort • Do not punish them for these behaviors • Talk to your care team if these behaviors cause problems or do not get better

<p>Elementary School (6 – 10 Years)</p>	<ul style="list-style-type: none"> • Understand more about serious illness but might think it only happens to other people • Might feel worried, anxious, or even guilty • Might have questions that you cannot answer • Changes with school, friends, or after-school plans can feel like a big deal 	<ul style="list-style-type: none"> • Be honest and open when talking about serious illness • Be ready to share a few more details • Let them know their feelings are okay • Check often so they can talk and ask questions • Try to make a plan with the school and stick to it • Help them stay connected with friends
<p>Middle & High School (11+ Years)</p>	<ul style="list-style-type: none"> • Teens understand serious illness more like adults do, but they have their own way of thinking about it • May seek answers on their own from friends or the internet • Might struggle with how they look • Might feel sad or down • May have strong feelings and mood swings • Feeling out of control while wanting more freedom can cause sadness or frustration • Might feel alone, different, or left out 	<ul style="list-style-type: none"> • Let them lead the conversation about their illness and care • Ask them to come to you with questions so you can help them find good answers • Check in often • Listen without giving too much advice or lectures • Talk to your care team if you notice big changes in their mood or if they stop enjoying things • Try not to take anger or outbursts personally • Give them space if they need it • Do not force them to talk • Do not be too protective • Try to balance their need for freedom with healthy rules • Keep an eye on their social life • Encourage them to stay close to their good friends
<p>Other Special Needs & Developmental Disabilities</p>	<ul style="list-style-type: none"> • Might need extra help for things not related to the illness 	<ul style="list-style-type: none"> • Use tips from the other age groups in this chart to support them

Appendix D: Helping Young Children Understand a Sibling's Illness

Helping young children understand a sibling's illness can be hard, but asking gentle and caring questions can help them process what is happening. Here are some examples of questions you can ask your children to help them better understand and share their feelings.

Question	Why Ask It	Example Follow-Up Answer
Do you know that [sibling's name] isn't feeling well right now?	To open a gentle conversation and see what your child knows	What have you noticed about [sibling's name] lately?
How do you feel about [sibling's name] being sick?	To let your child share feelings and worries	It's okay to feel upset or worried. How can I help you feel better?
Have you noticed anything that makes [sibling's name] feel better or more comfortable?	To encourage your child to think about helping their sibling	Maybe we can do something together to make [sibling's name] feel loved and supported.
Sometimes when people are sick, they may need to rest a lot. Do you know what [sibling's name] might need to help them rest?	To help your child understand why rest is important	It's important we help [sibling's name] get plenty of rest so they can feel better.
What do you think we can do together to show [sibling's name] that we care about them?	To help your child think of ways to show love	Maybe we can tell [sibling's name] a funny story or give them a big hug to show we care.
Do you have any questions about why [sibling's name] is in the hospital/doctor's office?	To clear up confusion and explain the situation	The doctors are there to help [sibling's name] get better, and they're doing everything they can.
It's okay to feel sad or worried about [sibling's name], but do you know we can still love them and be here for them?	To reassure your child that love and support still matter	How do you think we can show [sibling's name] love while they are resting?

What makes you feel better when you're not feeling well? Do you think that would help [sibling's name]?	To help your child think about comforting actions	Sometimes a warm blanket or a favorite toy can make you feel better. Maybe we can give [sibling's name] something they like too?
Sometimes it's hard to talk about feelings when someone is sick. Do you ever want to talk or ask questions?	To normalize talking about emotions	It's okay to ask questions. I'm always here to listen when you need to talk.
What do you think would make you feel better when you're worried about [sibling's name]?	To help your child find ways to cope and feel comfortable	Maybe we can play a quiet game or go for a walk together to feel better.

Appendix E: When Death Is Near: What You Might See

Every child's end-of-life journey is different. This can be a time of love, change, and saying goodbye. Your care team is here to support your whole family. Keep your child comfortable by giving them pain or breathing medicine as directed. These medicines do not speed up death when used the right way.

Here are some signs that your child may be nearing death:	
More Sleep	<ul style="list-style-type: none"> • They may sleep most of the time. • They may stop talking or responding. • Still talk to them. They may hear you. • Gentle touch may be comforting.
Not Eating or Drinking	<ul style="list-style-type: none"> • They may not want food or drinks. • This is normal as the body slows down. • Urine may be darker or less frequent. • Offer ice chips or a popsicle if they want them. • Mouth care is important to keep them comfortable. • Giving fluids through a tube may cause discomfort; ask your care team.
Cool Hands and Feet	<ul style="list-style-type: none"> • Arms, legs, hands, ears, and nose may feel cold. • Use extra blankets (but no heating pads as they can cause burns).

Changes in Skin Color	<ul style="list-style-type: none"> • Skin may look blotchy or darker. • Light skin may look pale or bluish. • This is called mottling and is normal.
Rattling in the Throat	<ul style="list-style-type: none"> • You may hear a wet or rattling sound when they breathe. • It is not painful and does not mean they cannot breathe. • Turning them on their side may help. • Medicine can sometimes reduce the sound; ask your care team.
Bladder and Bowel Changes	<ul style="list-style-type: none"> • They may lose control of urine or stool. • This is normal. Let them know it is not their fault. • You may need diapers or bed pads.
Confusion or Restlessness	<ul style="list-style-type: none"> • They may seem confused or do not recognize people. • They may pull at clothes or blankets. • Speak softly and clearly. • Tell them what you are doing: "We're turning you now." • Holding their hand, playing music, or reading may help.
Breathing Changes	<ul style="list-style-type: none"> • Breathing may become fast, slow, or have pauses. • This is a normal part of the body slowing down.
Withdrawal	<ul style="list-style-type: none"> • They may lose interest in toys, visitors, or favorite things. • They may want only close family nearby. • This may feel hard for loved ones but can bring peace to your child. • Your calm presence means the most right now.
Vision-like Experiences	<ul style="list-style-type: none"> • They may say they see or talk to people who have already died. • They may say someone is waiting for them. • These experiences are common and often comforting. • Do not argue or explain, just listen and be there.
Permission to Let Go	<ul style="list-style-type: none"> • They may be holding on to make sure you are okay. • Telling them it is okay to go can be a final gift. • You can say goodbye and tell them you will be all right. • If it fits your beliefs, say you will see them again. • You do not need to hide your sadness. Your love shows through your tears.

Appendix F: Ways to Deal with Difficult Feelings

Parents and caregivers need ways to handle hard feelings. Use these ideas to help you cope. Please know that even though this information may sound scary, the care team's first goal is to help prepare you and your child for what to expect. Remember that someone from the care team is always available to help you.

Ways to deal with difficult feelings:	
<p>Fear</p> <p>It is normal to feel scared when your child is seriously ill. Facing your fears and talking about them can help you feel less anxious.</p>	<ul style="list-style-type: none"> • Talk to someone you trust. Sharing your feelings can help you feel less alone. • Ask questions. If you do not understand something, ask. • Hold on to hope. What you hope for may change over time, but you can still dream and set small goals. • Laugh when you can. Spend time with people who make you smile. Laughter can lift your mood, even on hard days. • Set boundaries. It is okay to limit time with people who make things harder for you or your child.
<p>Anger</p> <p>It is healthier to let your anger out than to keep it inside. How you express it matters.</p>	<ul style="list-style-type: none"> • Find someone you trust to talk to. They do not need to fix things, just listen. • Anger can hide other feelings like fear or sadness. Talking it out can help you understand what is really going on. • Be careful not to hurt others with your words. If you are really upset, wait until you can speak calmly. • Tell others how to support you. Let them know you just need to talk and that you are not mad at them. • If you say something hurtful, saying "I'm sorry" can help heal the situation.
<p>Sadness</p> <p>It is ok to feel sad. It is a natural part of going through a hard time.</p>	<ul style="list-style-type: none"> • You may be feeling grief from all the changes and losses. • Let your feelings out. Talk to someone who makes you feel safe. Crying together as a family can help. • It is also okay to not feel sad all the time. Everyone needs a break from big feelings. • Try to find small positive moments like listening to music, reading, or sitting in the sun.

<p>Anticipatory Grief</p> <p>This is the sadness people feel before someone they love dies or while watching them suffer.</p>	<ul style="list-style-type: none"> • Set small, short-term goals that are still possible. • Talk with someone you trust and love about how you feel. • Do memory-making and legacy activities together as a family.
<p>Guilt</p> <p>It is normal for families to feel guilt when a child is very sick. Guilt can come from real or imagined things.</p>	<ul style="list-style-type: none"> • Talk about how you are feeling with someone you trust. • You can ask to talk with a social worker or chaplain from the care team. • Sharing your feelings is a healthy way to take care of yourself and your family.

Anticipatory Grief

Anticipatory grief is the sadness and worry people feel before someone they love dies. Siblings may feel scared, confused, or unsure about what is happening. Hospice teams help by talking with siblings in ways they can understand and by giving them safe ways to share their feelings, like drawing or playing. They also help families include siblings, so they feel supported and not alone during this hard time.

Physical Symptoms of Grief

When you are grieving, it is normal to have physical symptoms, such as:

- Eating more or eating less
- Trouble sleeping
- Feeling very tired or low on energy
- Headaches

Be kind to yourself. Give yourself the time and care you need as you go through this process.

Appendix G: Additional Resources

General Pediatric Palliative & Hospice Care Support

<p>NORD (National Organization for Rare Disorders)</p> 	<p>CaringBridge</p> 	<p>Children's Project on Palliative/Hospice Services (ChiPPS)</p> 	<p>Courageous Parents Network</p> 	<p>Pediatric Palliative Care Coalition (PPCC)</p> 
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Family Support & Caregiving Resources

<p>Caregiver Action Network</p> 	<p>Family Caregiver Alliance</p> 	<p>Make a Wish</p> 
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Disease-Focused Associations (Educate, Support & Connect Families)

<p>Chai Lifeline</p> 	<p>Child Neurology Foundation</p> 	<p>Cure Mito Foundation (Leigh Syndrome & Mitochondrial Disease)</p> 	<p>Global Genes</p> 	<p>National Tay-Sachs & Allied Diseases Association (NTSAD)</p> 	<p>Parent to Parent USA</p> 
<p>Rare Village Foundation</p> 	<p>SOFT - Support Organization for Trisomy 18, 13 & Related Disorders</p> 	<p>The Magic Foundation (Growth and Genetic)</p> 			

Tips for Families Seeking Condition-Specific Support

Start with trusted rare disease hubs like NORD and Global Genes to find support networks for your child's condition.

Ask doctors, specialty clinics, or genetic counselors. They often know about support groups in the US and around the world.

Join online groups, such as RareConnect, to talk with other families who have children with the same diagnosis.

Check social media or your local hospital's website (for example, Johns Hopkins support pages) to find helpful resources for your child's condition.

Appendix H: Glossary

Bereavement: Care that gives emotional, social, and spiritual support to people and families dealing with grief and loss. This can include counseling, support groups, helpful materials, and regular check-ins.

CHIP: Children's Health Insurance Coverage

CNA: Certified Nursing Assistant

Concurrent Care: Care for children with serious illnesses where they get medicine to fight the disease AND hospice care to manage symptoms and give support at the same time.

FLACC Scale: A way to measure pain in non-verbal children using their face, legs, activity, cry, and ability to console.

NORD: National Organization for Rare Disorders

Opioid: Type of medicine that can help stop very strong pain, like the kind people may feel after surgery or an injury. These medicines work by changing how the brain and body feel pain.

Palliative: Care or treatment that helps make someone feel better and more comfortable when they have a serious illness.

RN: Registered Nurse

TRICARE: A healthcare program for active duty military service members, National Guard, Reserve members, and their family members.

Global Genes



RareConnect



NORD



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