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St. Jude Children's Research Hospital

Facing Difficult Times

*A resource for families
coping with serious illnesses*



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You have just been given news you never wanted to hear. Your child's disease has come back or progressed. We know this is difficult to hear, and we are here to help in every way we can.

This resource book has answers to many questions you might have. It is based on the experiences of the St. Jude staff and many St. Jude parents. The book is yours to use when you need it. Some topics might be more important to you at different times, and that is OK. It might also answer questions you are not ready to ask or reinforce a thought you already had.

We hope this book will help you with your concerns and give you ideas about how to help your child. Always know that we are here to answer your questions and to help you through this difficult time.

Facing Difficult Times was produced by the staff of St. Jude Children's Research Hospital, including the Palliative Care Task Force, Quality of Life Service, Patient Education, and Biomedical Communications.

The information in this booklet is not intended to take the place of the care and attention of your child's doctor or other professional medical services. Our aim is to promote active participation in your child's care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your child's doctor.

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Reaching the St. Jude Staff

*Use this sheet to record the names and contact information of staff
members who will be helping you through this difficult time.*

Primary Care Team (Clinic): _____

Primary Attending Doctor: _____

Inpatient Attending Doctor: _____

Resident Doctor: _____

Nurse Practitioner/Physician Assistant: _____

Clinic Nurse: _____

Inpatient Unit Nurse: _____

Social Worker: _____

Clinical Nurse Specialist: _____

Chaplain: _____

Child Life Specialist: _____

Dietitian: _____

Physical Therapist: _____

Pain Team Specialist: _____

Quality of Life Team: _____

Hospice: _____

Family Pastor: _____

Others: _____

St. Jude Resources

Your primary care team

All St. Jude patients have a primary care team. The team includes an attending physician (regular doctor), a nurse practitioner or physician assistant, and a nurse. Your child may also have a hematology-oncology fellow assigned to help with care. The care team, you and your family, and your child will make decisions about your child's care together. You will decide on treatment, determine what you and your child need, and work with other doctors or staff to fill these needs. You should feel comfortable contacting your primary care team whenever you have concerns.

The clinical staff

The St. Jude clinical staff is committed to giving your child the very best medical care. We will tell you and your child everything you want to know about your child's disease, the expected outcome, and the treatments available. We will also tell you if your child's condition changes. Our hospital staff includes doctors, nurse practitioners, physician assistants, nurses, and other staff members. We are here to talk with you about your child's condition and what may happen in the future. Although you may feel uncomfortable discussing sensitive issues, our staff has a great deal of experience caring for seriously ill children and their families. We are here to help you.

Social Work

Medical social workers are trained to counsel patients and families. They can help you and your child deal with:

- ✧ Having a serious illness;
- ✧ Coping with treatment;
- ✧ Learning that a cure is not possible; and
- ✧ Coming to the end of life.

A social worker can help you make decisions about care and treatment options. Your social worker also can counsel patients and family members, answer questions, and give emotional support. For adult patients, social workers provide information about advance directives. An advance directive is a record of the kind of treatment a person wants when she cannot speak for herself. If you have an advance directive, medical staff will know what you want even if you cannot communicate with them.

If your child dies, a social worker can help with:

- ✂ Planning a funeral;
- ✂ Clarifying help available from St. Jude;
- ✂ Exploring other resources for financial help;
- ✂ Addressing family needs;
- ✂ Leaving St. Jude or hospital housing; and
- ✂ Taking your child's body back home, including to another country.

If you have questions about any of these issues, please feel free to ask a social worker at any time.

Chaplain Services

Your family's spiritual and religious needs are very important. You may be making difficult decisions or simply need someone to listen to you, sit with you, or pray with you.

Our chaplains are here to serve as spiritual guides and companions. They can help with specific needs or help you find local churches, religious institutions, or clergy from your tradition. If you have spiritual questions about hope, meaning, and faith, our chaplains can talk with you.

Chaplains are not here to judge you or change what you believe. Their goal is to meet you where you are and help you explore how your faith can be a source of strength and comfort for you during the most difficult times you will ever face. Our chaplains provide grief counseling, religious counseling, religious sacraments, inspirational literature, and visits, including prayer.

To reach a chaplain, call extension 3672 or the hospital operator, or ask your child's social worker, nurse, or doctor. St. Jude has a chapel on the first floor of the Patient Care Center. It is always open and is a quiet place for you to pray or meditate.

Child Life

Child life specialists work with you and your child's care team to meet your child's needs. These can be:

- ✂ Emotional needs;
- ✂ Child development;
- ✂ Education needs related to diagnosis and treatment;
- ✂ Distraction, play, and relaxation.

Using knowledge of your child's culture, environment, language, and background, our child life specialists will develop a therapeutic plan. A child life specialist can also help your child's brothers and sisters cope with their feelings. They can support you in talking with your child and her brothers and sisters about serious illness and death.

A child life specialist can help your child and family create a legacy through expressive activities, which could include memory boxes, hand molds or handprints, voice recordings, and other artwork.

Clinical nurse specialist

A clinical nurse specialist (CNS) is part of your child's care team. Your child's CNS can help with:

- ✂ Teaching you to give IV (intravenous) fluids or medicines outside the hospital;
- ✂ Feeding (including G-tube feeding, in the hospital, at home, or in St. Jude housing);
- ✂ Plans if your child leaves the hospital; and
- ✂ Home treatment or hospice care.

Your child may be able to have treatment at home. A clinical nurse specialist can help you decide if this is the best choice for your child, and if so, what you will need. Your child's CNS can help arrange other nursing staff or services if you need them at home.

If you choose hospice care for your child, your CNS will talk with your child's care team about:

- ✂ Insurance;
- ✂ Equipment or supplies you will need at home;
- ✂ Any help you might need to care for your child; and
- ✂ Hospice services for children in your area.

The clinical nurse specialist will talk with you about how hospice can help your child and give your child's regular doctor, the hospice staff, or both all the details they need. You will be able to talk with St. Jude staff if you have questions or need advice. How much St. Jude is involved is up to you and the hospice staff.

Clinical Nutrition

A St. Jude dietitian can help your child get the food and supplements that will best meet your child's changing needs. A dietitian can:

- ✂ Teach you and other caregivers about the best nutrition for your child;
- ✂ Keep track of your child's diet to see if any changes are needed;
- ✂ Create a nutrition plan to meet your child's changing needs;
- ✂ Talk with you about diets that might help your child feel better; and
- ✂ Help manage side effects of treatment.

If your child is admitted to the hospital, a dietitian will talk with you about your child's needs. You may also talk with the dietitian after your child leaves St. Jude.

Pharmacist

The pharmacist is a member of your child's care team. A pharmacist can help with:

- ✂ Making sure your child has good nutrition;
- ✂ Managing the level of medicine in your child's blood;
- ✂ Controlling pain;
- ✂ Managing symptoms; and
- ✂ Giving you information about your child's medicines.

The pharmacist can tell you how each of your child's medicines works. This includes antibiotics, pain medicine, and chemotherapy drugs. A pharmacist is there to make sure your child's medicines work as well as they can, that the dose is safe for your child, and that you and other caregivers understand how to give medicines.

If your child leaves St. Jude, the pharmacist will work closely with the clinical nurse specialist to help you make the transition. Your pharmacist also will work with your child's care team to determine what medicines you can give your child at home. The pharmacist will keep track of your child's medication plan to make sure it is working and will make any changes your child needs.

Rehabilitation Services

Rehabilitation Services at St. Jude include audiology (help with hearing problems), occupational therapy (daily living skills), physical therapy, and speech-language pathology (speech therapy). If your child has already used some of these services, you can continue to use them. If your child has not used these services, you should know they can help your child feel more comfortable and function better. A therapist can help your child:

- ✂ Be more physically active;
- ✂ Be more comfortable;
- ✂ Stay independent as long as possible; and
- ✂ Communicate by using special equipment.

If you are interested in Rehabilitation Services, ask your child's doctor.

Respiratory Care

A respiratory therapist can help your child breathe easier. Respiratory therapists can:

- ✂ Help your child get enough oxygen;
- ✂ Keep track of oxygen and other gases in your child's bloodstream;
- ✂ Diagnose lung or breathing problems;

- ✂ Manage your child's ventilator or other breathing equipment; and
- ✂ Talk with the doctor about treatment for your child's breathing.

If your child has problems breathing or is receiving any breathing treatments, feel free to talk to the respiratory therapist if you have questions.

Pain Management Team

Your child's doctor may ask the St. Jude pain team to help with treatment. This team includes doctors, nurses, psychologists, physical therapists, and pharmacists who are trained to help reduce pain in children. They will also watch your child for any side effects of pain medicine, and treat them if they occur.

Quality of Life Service

Your child's doctor may ask the St. Jude Quality of Life Service to help with treatment. This team has specialized training in:

- ✂ Pain and symptom control;
- ✂ Communication and decision making;
- ✂ Hospice care; and
- ✂ Coordinating end of life care.

Patient housing

The St. Jude patient housing program is made possible by generous donors. Each facility is set up for patients and designed to be like a home for out of town families. Housing assignments are based on how long your family will be staying in Memphis and what kind of care your child needs. The St. Jude patient housing staff will work with your child's care team to help meet your needs. If you have special needs, please talk with the housing social worker or your child's social worker.

School program

The St. Jude School Program can help your child continue normal school activities.

If your child is not recovering, the program can still provide services as long as your child can benefit from them. We will work with you and your child to determine what is best for your child. If going back to school or returning home is the best option, the St. Jude School Program staff can help you and your child make the transition.

Clinical Psychology

Clinical Psychology provides counseling and treatment to patients of all ages and their families. Your child's doctor or care team can help you start using these services. The psychology staff can help with:

- ✂ Treating depression or anxiety;
- ✂ Family conflict and other conflicts or problems;
- ✂ Problems coping with illness, loss, or other issues;
- ✂ Pain; and
- ✂ Managing anger and stress.

The psychology staff also provides counseling for individuals and families. They can help you with relaxation training, hypnosis,

behavior management, grief counseling, and exams to determine your child's mental abilities. Our staff also can help you find psychologists, psychiatrists, other mental health providers, and education specialists in your home community and provide referrals.

Interpreter Services

Patients and families have a right to receive information about medical care in a language they understand. If you have family members who speak limited English, you should know that they have 24-hour access to qualified interpreter services at St. Jude.

During difficult times, medical interpreters can relieve English-speaking family members of the added stress of interpreting for their loved ones. St. Jude has approved face-to-face interpreters for Spanish, French, and Portuguese. Professional interpreters are available onsite from 8 a.m. to 5 p.m., Monday through Friday. In emergencies, medical staff can reach the hospital interpreter after hours.

For times when face-to-face interpreters are not available or when other languages are needed, our 24-hour telephone interpreting service also offers trained over-the-phone interpreters in more than 150 languages. This service is available anytime from any hospital telephone. For face-to-face interpreters, simply call the Interpreter Services office at 901-595-2983, ask a St. Jude caregiver to provide an interpreter, or call the main hospital number at 901-595-3300.

Research participant advocate

The St. Jude research participant advocate helps patients and families decide about taking part in research at St. Jude. Research studies are important and help find cures for disease. You should carefully consider any decision to take part in a clinical trial (research study). The research participant advocate can help you and your family find the information you need about taking part in research.

The advocate can be there when you discuss the informed consent process and answer any questions you may have. The research participant advocate is part of the St. Jude Office of Human Subjects Protection and sits on the St. Jude Institutional Review Board (IRB). You can reach the St. Jude research participant advocate at 901-595-4644 or toll-free at 1-866-583-3472.

In the future we may ask you to take part in research that may help us learn more about childhood cancer. If you agree to take part, your input may involve questionnaires and surveys. We may learn more about the causes of childhood cancer and how better to treat it. The research may involve reviewing medical and clinical records, research records that already exist, and studying blood and tissues that have already been collected. We will contact you to see if you are interested when these new studies are developed.

Family Resource Center

The Linda R. Hajar Family Resource Center is on the second floor of the Patient Care Center. In the resource center, you can access the Internet on our computers, send faxes, and use the extensive book collection that includes pleasure reading and information for patients and their families.

Notes:

Making Difficult Decisions

The following questions and answers may help you make difficult decisions about your child's care. If you have other questions, please feel free to ask the St. Jude staff.

How much do I tell my child?

Every situation is different, and every child has a different level of understanding. You know your child best, and during the course of illness, you have learned how much your child wants to know and how she handles information. At St. Jude, we have learned that even young children may understand complex situations and might want to help make difficult treatment decisions.

You can read the section called “How to Talk to Your Child and Others” for more details on talking with your child. Feel free to talk with your child's care team, a child life specialist, chaplain, or a social worker about what to say. You can also ask someone else to talk to your child for you.

What kinds of decisions will I be making?

- ✂ Whether to continue your child's cancer treatment or whether to stop it
- ✂ Whether your child should be in a research study (clinical trial), which will probably not cure your child's disease but might give her more quality time or might help future children
- ✂ Whether your child should have treatment that could help her live longer (radiation, chemotherapy, surgery)
- ✂ How your child's symptoms should be treated
- ✂ If your child should have a do not resuscitate (DNR) order (learn more about DNRs in the section called “Planning Your Child's New Treatment Goals”)

Who can help me make decisions?

Your child's primary care team can give you the most support. Many families also ask for help from other staff, family, friends, and spiritual leaders. This book explains how specific people can help care for your child. Many of these staff members also can help you make hard decisions.

What should I consider when making difficult decisions?

Every situation is different. However, these are some things you might want to consider:

- ✂ What your child wants
- ✂ Staff recommendations
- ✂ The overall goal of treatment
- ✂ Your feelings about what a good parent would do
- ✂ Religious faith or moral beliefs
- ✂ How the decision affects your family
- ✂ Pursuing comfort when cure is no longer an option
- ✂ Avoiding treatment if your child is suffering and treatment is not likely to work

These are some reasons children give for making the difficult choices they make:

- ✂ Avoiding treatment that will make me feel worse
- ✂ Meeting life goals (going to graduation, prom, camp, wish trip, etc.)
- ✂ Wanting comfort care when cure is no longer an option
- ✂ Not wanting to continue cancer treatment
- ✂ Seeing what has happened to other patients around them
- ✂ Believing further treatment cannot help
- ✂ Believing they are going to heaven
- ✂ Helping their families get ready for their death
- ✂ Being concerned for others

Will the staff support me in my decisions?

The St. Jude staff is committed to supporting you in making the best decisions possible for your child. One of the best ways to make sure this happens is to tell the staff your reasons for making a decision. Also, please tell us what you need and how we can help.

How can I help my child's medical team?

Tell your child's primary care team what the goals of care should be. If your child is old enough, you and your child can decide what you want together. For example, a goal could be "no pain," or "I want my child to do normal activities for a child her age." Because these goals can change with time, please talk with the St. Jude staff about what you and your child would like. Your goals will help your child's medical team make suggestions about how to care for your child.

The St. Jude staff will never know your child as well as you do. We want you to continue to be your child's strongest advocate. Any time you think the team should be doing something different, please tell us. If you think your child is suffering or could be doing better, tell your child's care team. We always want to discuss your concerns.

How will my decision affect the care my child can receive from St. Jude?

Every case is different. The care your child receives depends on the goals of care. Your child's doctor, nurse, or another staff member on the primary care team can talk with you about this. The St. Jude staff is committed to supporting the decisions made by patients and families about their care.

What if I change my mind?

As time goes by you might want to change your mind, or it may be important to stick with your earlier decision. If you want to change your decision or your child's goals of care, the St. Jude staff will do

its best to support you. Your child's team can talk about the goals of your child's care with you and help you decide what should happen next.

What if I want to take my child home?

Depending on what your child needs, the care team will try to help you meet this goal. The St. Jude pharmacists and clinical nurse specialists are experts in helping children receive care at home or in St. Jude housing as well as in the hospital. Every situation is different, but if you and your child want to go home, the St. Jude staff will do their best to make it happen.

Should I take my child to another hospital?

If you are from outside the Memphis area, you might want to have a doctor in your local area care for your child. If you think your child is not getting the best treatments at St. Jude or you find out about a treatment your child is not receiving, talk with your child's medical team. It is important to talk about any treatments you may discover online, so you can learn as much as possible and ask questions. If you have questions about treatment at any time, please ask your child's doctor, nurse, or someone else at St. Jude.

How can I help my other children?

Your other children are affected by your sick child's illness and helping them is important. Set aside times when they can talk to you, and ask a friend or relative to talk with them when you are not there. You might want to talk with your social worker, chaplain, or child life specialist about other ways to help them. The "St. Jude Resource" section of this book discusses ways your child's care team can help. You might also want to read the section called "How to Talk to Your Child and Others," which discusses how to help your child's brothers and sisters.

What if my decision is different from what I think the care team wants?

You understand your child best. The St. Jude staff and your child's primary care team are here to help you make decisions. If you feel your child's care team wanted you to make a different decision, talk with your social worker or another staff member. The hospital ethics committee and the St. Jude research participant advocate can also help.

Should I consider a phase I trial for my child?

Being in a phase I study gives you and your child the chance to help doctors understand new medicines that have not been tested in many children. Doctors know how these medicines work in animals and in adults but not in children. They think they could possibly help treat childhood cancer. Phase I studies help find the largest dose of medicine that can be given safely to children. They also help researchers learn what its side effects are. Some phase I studies help find out the best way to combine different medicines.

Patients in phase I studies are not likely to get better from the experimental treatment. Taking the medicine might cause side effects that would make your child feel worse. Your primary care team can talk with you about these options and help you decide if a phase I study is right for your child.

What about complementary and alternative medicine or other non-standard treatments?

Talk to your child's doctor about these other treatments. The St. Jude staff are very cautious about treatments that may harm your child and have not been proven to help. If your child's doctor does not believe the treatment will harm your child, and you would still like to try it, your child's St. Jude pharmacist can research possible side effects and reactions with your child's other medicines.

My child is over 18 and has been actively involved in decision making during her treatment. We were asked if she had an advance directive. What is this?

An advance directive is a written plan for how an adult patient wants medical care performed if the patient cannot speak for herself because of a serious illness or injury. There are two types of advance directives. One is the Appointment of Health Care Agent, also known as a durable power of attorney for health care. To do this, you choose someone you trust to make decisions for you and to act on your behalf if you are unable. The other advance directive is a detailed plan of care called an Advance Care Plan (also known in some states as a living will or a health care plan). Your St. Jude social worker can give you more details about these options and assist you with the forms if your child wants to complete an advance directive. Also, your social worker can share an educational sheet with you called “Do You Know... Advance Directives.”

Notes:

Planning Your Child's New Treatment Goals

You and your child need to know:

- ✧ About possible medical treatments,
- ✧ Your child's detailed medical condition,
- ✧ Whether doctors expect your child to get better or not, and
- ✧ The choices you must make.

Planning your child's care in advance with the primary care team will help you make difficult decisions later. Two important parts of your child's care plan are talking about the prognosis (whether doctors expect your child to get better or not, when, and why) and the goals of care.

Prognosis

Your child's doctor will tell you whether your child is expected to get better or not, when and why, and sometimes how soon this could happen. Sometimes, it is hard for the doctor to tell exactly when and how your child will get better or sicker, or if your child will die. Knowing what is most likely to happen can help you and your family when things seem uncertain.

If you understand what will probably happen, your child will likely have a better quality of life. It is crucial to talk about your child's prognosis with the primary care team, so you can make decisions about treatment together.

You might talk about whether a cure is possible and how treatments will affect your child. If a cure is not likely, you might talk about whether treatments can make your child feel better and able to enjoy life more.

Goals of care

Having goals for your child's care will help you make hard decisions. Remember that each patient and family is different, and there are no right or wrong decisions, only what is best for your child and family.

These are some possible goals of care:

- ✂ Curing your child's disease
- ✂ Helping your child live longer
- ✂ Helping your child to keep doing usual daily activities, such as getting dressed or brushing teeth
- ✂ Keeping your child free from pain or discomfort
- ✂ Helping your child enjoy life more in general (quality of life)
- ✂ Reaching a specific life goal, such as taking a trip or going to the prom
- ✂ Helping your family and loved ones cope with your child's illness
- ✂ Finding meaning in your child's life
- ✂ Helping doctors learn more about your child's disease so they can help other children with the same disease
- ✂ Knowing you did everything you could to help your child

You might have some or all of these goals or other goals. Many families have different goals at different times. A recent study showed that about half of families with sick children had 2 main goals:

- ✂ Keeping their child free of pain or discomfort or helping the child have less pain
- ✂ Treating their child's cancer so the child could live longer

Some decisions you might make

Where do I want my child to receive the rest of her care?

You may need to decide between staying at St. Jude and taking your child home. No matter what you decide, your child's doctors will try to keep her as comfortable as possible. If your child is in a research study for cancer treatment, you may need to stay in the Memphis area.

If going home is important to your child, the St. Jude staff can help you find care in your area. For more details, see the "St. Jude Resources" section of this book. Taking your child home from St. Jude is easier when you have time to plan. If you think you might want to take your child home, talk to your child's doctor or nurse as soon as you can. Your child's care team can work with doctors and other health providers in your area to make sure your child gets the care she will need.

What medical procedures could my child have?

There are many medical procedures that could keep your child alive longer. Some of them will prolong life but will not always make your child more comfortable. The procedures you choose will depend on your goals for your child's care. You might want to have some but not others, or you might want all of them or none.

Some of these procedures include the following:

- ✂ Putting a tube in your child's throat and using a machine to help her breathe
- ✂ CPR – pushing on your child's chest to try to start the heart after it has stopped
- ✂ Doing blood tests
- ✂ Giving antibiotics or other medicines to fight infection
- ✂ Feeding your child through a tube

- ✂ Going to the hospital if your child has sickness, pain, or other symptoms
- ✂ Having surgery, radiation or both to treat symptoms caused by a tumor
- ✂ Giving blood transfusions to help your child's symptoms
- ✂ Having chemotherapy that might make your child live longer

Is it OK to stop trying to find a cure?

If your child is not likely to get better, you and your child may need to decide when to stop trying to cure the disease. This does not mean you are giving up. You will have different goals, such as helping your child live as long as possible and feel as comfortable as possible. Talk with your child's doctor and primary care team about when some treatments should stop. You may want to use the form "Physician Orders for Scope of Treatment" (POST) to help you talk with your child's team.

What is a "Do Not Resuscitate Order" (DNR) or "Physician Orders for Scope of Treatment" (POST)?

A DNR order is a request to allow a natural death (one where certain treatments will not be given to prolong life) for your child. The POST form lets you tell the medical team what kinds of treatment you do and do not want for your child. If the POST form says that you wish a natural death for your child, the medical team will not do CPR if your child's heart stops or she stops breathing. An order to allow a natural death is most appropriate when using medicines or procedures to restart your child's heart or breathing might cause harm or will not help her live much longer or be more comfortable.

Depending on your goals of care, you and your child's primary care team will decide what kind of treatment you want for your child. After you decide on the kind of treatment you want, your child's doctor will fill out a POST form to let the medical team know your

wishes. Be sure to talk with your child's doctor and care team when you know your child's disease will not get better. This will help your doctor be sure that your wishes are written in your child's chart. If you wait for an emergency, it may be harder for your child to get the treatment you want.

If you take your child home, you may want to have a POST form in your child's chart. This will let the medical team in your area know what you want for your child. If you do not let them know, they will do CPR if your child's heart or breathing stops. Your primary care team can help you with this form before you go home.

Can I change my mind about the decision I have made?

Yes. Talk with your child's doctor at any time about changing the treatment chosen on the POST form. If you are at St. Jude, your child's doctor and primary care team will be here to help you with concerns as your child's situation evolves. It is important to think about how your decision fits with the goals of your child's care. If you have taken your child home, talk with your doctor there. You can also choose to have the home doctor consult with your child's St. Jude doctor.

This is a difficult decision. How do most parents decide?

Many parents of St. Jude children who have died chose a DNR order. You might know right away how you will decide about a DNR. You also might want to talk with your family or friends, your child's pediatrician, other parents at St. Jude, or your child before you decide. Talk with your child's primary care team and think about the goals of your child's care. Your child's doctor, nurse, a chaplain, or social worker at St. Jude can help you think about your choices and make the best decision for your child. See the St. Jude Resources section of this book for staff who can help you make decisions.

Notes: _____

How to Talk to Your Child and Others

When you receive bad news from your child's doctor, you will probably have many different thoughts and strong feelings. You will probably have many questions about how to help your child. You might also wonder how to talk with your child about the news. If possible, give yourself time to understand this new information and to experience your emotions. There are resources to help you cope at St. Jude and at home. Ask for help and do not be afraid that you might bother someone by asking. Tell your family members, friends, and St. Jude staff what you and your child need. Everyone will work together to help you at this difficult time.

Before you talk, know how children react

As you prepare to talk with your ill child, her brothers and sisters, or friends, it is helpful to know how children respond to bad news. If your child is very young, she might become clingy or seem self-centered. If your child is older, she might act angry, act out by doing inappropriate things, withdraw from friends and family, or act older than she is. Your child might do these things to cover up feelings. She may feel afraid, angry, sad, or guilty. Your child might also feel angry and frustrated because the illness is disrupting her life and she feels like she is not in control.

Also, your child might react less than you expect at first. When you tell her the news, she might act sad or angry and then go play. She might not respond at all, or she might act sad sometimes and play at other times as if nothing bad has happened. Think about how your child has responded to bad news in the past. What has helped her in the past might help you support your child now.

Your child might express her thoughts and feelings through art and play. She may draw dead or dying people or disturbing pictures. Ask your child questions that require more than a yes or no answer, such as "Tell me about your picture." This can help you learn more about your child's feelings. Playing can also help your child bring out feelings in her own way. If your child is a teenager, she might want to spend more time with friends and may withdraw from your family. This might seem selfish but is actually normal at this age. If your child's behavior concerns you, talk with a St. Jude social worker, child life specialist, or psychologist.

Honesty is best

It is best to be honest with your child about what is happening. Unlike when she was first diagnosed, your child knows about the disease, has asked questions, and may have seen what happens to other children in the hospital. Your child can often sense when other people, especially you, are upset. She might also be anxious about

the illness. Even children as young as 2 and 3 years old can figure out that something is wrong. Your child might watch you, the St. Jude staff, or other family members to figure out what is going on, even if she does not seem to be paying attention.

Here are some things children have said to St. Jude staff:

- ✂ I could tell it wasn't good because my nurse had a sad look on her face and didn't tease me like she usually does.
- ✂ My mom keeps leaving the room to talk to dad on the phone.
- ✂ Daddy looks like he has been crying and won't look at me. I know something is going on, and they just won't tell me.

Your child might try to talk about difficult topics with you. She might feel the need to protect you from her illness or from feeling sad. Your child might not ask questions or express feelings because she feels it will be too emotional for you. Studies show that being honest with children helps them cope better with whatever happens. If you do not give your child honest information in words she can understand, she will be left to imagine what is happening. These thoughts can often be scarier than the truth.

You know your child best, so you are the best judge of what you should say and how you say it. Tell your child as much as she needs to know and can handle at that time. Try to answer your child's questions completely but do not overwhelm her with details. Explain what will happen next. If you like, someone from your child's care team can be there when you talk to your child.

Give your child some time to think about what she just heard, and the chance to ask questions. Let your child know it is OK to ask questions at any time. Tell her that although you are sad, you will always be with her to help her through this. Also, the care team will keep taking good care of her and will make sure she is comfortable.

Emotion is normal and healthy

Sharing your own feelings is helpful to your child. If you are emotional or start to cry, you are showing your child that feelings are OK. You are also showing that you can be sad and still manage. Sometimes children want to protect their parents, because they are afraid emotions will make them upset. Show your child that emotions are normal and expected. This can help her understand that her feelings are normal.

Remember that children are often quite strong and resilient. We all learn and grow emotionally during hard times. You may find comfort in listening to your child's thoughts and feelings. When your child talks to brothers, sisters, or friends, they might build memories that will help in times to come. Your child may need to complete a task or give someone a special message. This may be her way of contributing to society and should be encouraged.

Be prepared for difficult questions

Your child might ask if she is going to die. Many children think bad news, especially the news that their disease has come back or gotten worse, means they will die soon. Your child might believe she is already dying. Even when the disease comes back or grows, it can take a long time for your child's illness to come to its end. You might need to help your child understand that it is time to change medicines or treatments but is not yet the time when no more medicines will help.

If your child is very young, she might know the illness is serious but not know that the disease coming back can mean death. No matter how hard it is, try to give your child an honest answer. She needs to know she can trust you to tell the truth.

Try to plan what to say if your child asks if she is going to die. Listen carefully to what your child asks. Use comforting language to tell your child that sometimes children die of their illnesses. These are some things that parents might say:

- ✚ “I don’t know what is going to happen next. The medicine you were taking is not working on your illness. Sometimes children do die from this, but I don’t think that is happening now. We are working with your doctors to find new medicines to try. We will be with you no matter what.”
- ✚ You can learn more about what your child is thinking by saying something like this: “You know we all will die one day. I wonder why you are thinking about this today.”

These are some things you can do if your child asks about dying:

- ✚ Listen carefully to the question
- ✚ Answer what your child asks without too much detail
- ✚ Listen for more questions
- ✚ Watch your child’s body language, such as no eye contact, fidgeting, changing the subject, getting up, or telling you “enough.”

Tell your child what you know and what the doctor and care team will do about it. If your child does not talk about dying, you can bring it up if it seems like the right time. You can ask your child if she is worried or afraid, or if there is something she would like to talk about with you or anyone else. If she has had friends who were St. Jude patients, she might already know children who have died and might wonder what will happen to her.

Include your other children

Talk to your other children. Since they have already been affected by your child’s illness, they are familiar with many issues and are likely to have questions. You might want to practice what you will say with someone who understands your situation, such as a member of your St. Jude care team or your social worker.

Your other children will probably ask some of the same questions as your sick child. They will also want to know how the change in your sick child’s condition will affect their lives. Spend time with them, and encourage them to ask questions when they are ready. You might need to tell them that someone will be there for them. It also can help to find someone, such as a family member or friend, who can be with your other children when you are with your sick child. Encourage your children to come to you with questions or concerns they might have about things they have heard.

Talking to your child about dying

One of the hardest things you will ever do is telling your child she is going to die. It can help to know that most children who are not getting better already know death is coming. It might even be a relief to talk about what you already know. Your child is not getting better, and there is no more treatment that can help. Your child may have gone along with treatment she did not want because she thought it was important to you. She might have started to get ready for death long before you.

Your child might give you hints that she is ready to talk about death and dying. The St. Jude staff know that children sometimes talk about dying when adults do not. These are some things that other St. Jude children have said:

- ✚ I am going to see my grandpa (who died last year) soon.
- ✚ When my medicine doesn’t work anymore, I am going to play with Jesus.
- ✚ I don’t need to shop for school; I’m not going next year.
- ✚ I’m not afraid to die.
- ✚ I’m tired and want to go home.
- ✚ When am I going to heaven to be with... ?

One little girl wrote her “fortune” while playing a game: “You’re going to heaven soon.” Some children draw angels, pictures of heaven, or cemeteries.

If your child says or does these things, your first reaction might be to respond in a way that avoids talking about death. You might say, “No, you’re not going to see grandpa,” or “Of course you are going to school.” This is not a talk you ever thought you would have with your child. Take a deep breath and ask your child to tell you more about seeing grandpa, playing with Jesus, not going to school, not being afraid to die, going home, the fortune, or the pictures. This can help your child talk about what she is feeling and thinking. It might make you feel better to know your child’s questions so you can help with answers and address concerns.

Finding the right words to say is important

You know your family’s experiences, values, beliefs, attitudes, and words better than anyone else. Your beliefs will help you talk about the end of life and help you find the right words. If it is right for your family, you may ask a minister, rabbi, or chaplain to help answer your child’s questions. There are also non-religious books that can help. The child life staff, the hospital chaplains, or your social worker can help you find books to help you discuss dying. It is most important to be honest with your child. Encourage her to talk with you, and reassure her that you will be with her and make sure she is comfortable. Some parents say having these difficult talks was actually helpful. They were comforted by their child’s thoughts, feelings, and experiences.

Your child might start to plan for her death. She might talk about who should get her special toys and clothes, what music to play at her funeral, or what she wants to wear. Talking about her plans is one way your child can cope with her feelings and needs. She will probably ask questions and talk when she wants answers. These conversations often happen at night, when everyone is in bed and

activities have stopped. You should consider your child’s age and how much she understands when talking with her about death.

For children 2 through 6

If your child is between 2 and 6, she is starting to understand what death means. However, she might have trouble understanding why things happen. She might believe things happen by magic, and that her behavior, actions, or thoughts can change the illness. She will be curious about the changes that are happening, and without simple information, she will probably make up an explanation. Since she does not understand that death is permanent (cartoon characters die and come back to life over and over), your child will probably be most worried about leaving you and going to a strange place. Depending on your religious beliefs, talk with your child about what death might be like, and tell your child you will stay with her as long as you can. Some parents comfort their children by saying they will join them soon and by talking about who might be waiting for them, such as grandparents, friends, and pets.

For children 7 through 11

If your child is 7 to 11 years old, she probably knows that death is permanent and caused by something beyond her control. She may worry about whether dying will hurt and about leaving you. Your child may have started to develop her own religious beliefs. If so, listening to her beliefs, sharing your beliefs, and possibly talking with your minister, rabbi, or a counselor might help. You might not be sure yourself of what dying will be like for your child. Your doctor and care team can give you information about this. Tell your child that you will be there to support her and that the doctor will be sure she is comfortable.

For teens and young adults

If your child is a teenager or young adult, she will have a greater understanding of death. However, she will tend to shut out thoughts of her own death. Your child may worry about how her death will

affect your life. She may struggle to develop her own identity, find independence from you, and control what she can. This is normal for teenagers and young adults. Often, teens and young adults have strong ideas about how they want to live in their remaining days.

Ask your child questions

Do not assume that you know what your child is thinking or what she fears. The things that upset you may be different from the things that scare or confuse your child. If you ask questions and listen to your child, you will learn what is most important.

Talk with your child about whether she wants to be at home or in the hospital when she dies. Ask if there are things she would like to do before dying. Are there special places your child wants to go or friends she would like to see? Your child might want to decide who should have her toys, clothes, and other things after she dies.

If your child is older, she may want to help prepare her own memorial service and funeral by telling you what she wants and who should take part. Your child can pick out special music, poetry, clothing, scripture verses, and mementoes or pictures to display at the service. This can give your child some sense of control over what happens.

Telling other people

You can decide who needs to know about the change in your child's condition. It may be too hard for you to tell all your friends, family, and co-workers in person. You might want to use e-mail, or have a friend or family member call other friends and relatives. This is both a precious time and difficult time for you and your sick child. You do not have to spend a lot of time on the phone if it makes you tired or you would rather do something else. You may want to specify a family member as the "go to" person for information.

Talking to your other children

You might want to talk with your other children about your ill child's wishes and how they will be affected. Allow them to talk about their needs and concerns. Let them know they do not need to feel guilty about their own feelings and needs. Talk with your other children about whether or not they want to be there when your ill child dies. Let them know you will respect their wishes as much as possible. This can be a time to answer questions and comfort them.

The final stages of life can be a confusing and frightening time for everyone. Tell your children that everyone will do all they can to keep them comfortable. Your child's care team and other St. Jude staff will be there for you every step of the way, supporting you in whatever way we can. The St. Jude chaplain, child life specialist, social worker, and psychologist may be especially helpful.

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When There is Family Conflict

Having a very sick child brings family members together, sometimes for a long time. Just being together more than usual can be stressful, and your child's illness makes this more difficult.

Family members who get along at other times might argue or disagree during this stressful time. If some family members do not get along, the conflict may get worse when your child is very sick or dying.

This section of the book can help you:

- See possible problems in your own family;
- Think about how to manage family conflict; and
- Find ways to create a calm, pleasant environment for your sick child.

Things that can cause conflict

- Custody issues and amount of time spent with the child by divorced parents and their family members
- Family members who come back to see your sick child and get involved as she comes to the end of her life
- Conflict between people who have cared for your child through treatment and those who have not been there
- Different ideas about your child's treatment
- Family members feeling left out or feeling they do not have control
- Teenage or young adult patients who disagree with their parents about life and treatment goals
- Different ideas about how to discipline a sick child

Emotions that can cause conflict

- Anger at your child's situation
- Loss of control, which can make people feel more angry or sad
- Guilt over not being able to fix the problem, having to be at home caring for the rest of the family, or having to leave your other children at home
- Depression
- Grief
- Fear of the unknown, possible loss, uncertainty

- ✂ Emotional exhaustion
- ✂ Feeling overwhelmed

Stress, being tired, and not sleeping well can make you and other family members feel more emotional.

Planning for special time

When you know you and your child might not have much time left together, you may want to do some special things. These questions can help you think about things to do with your child.

- ✂ What is important to your child now?
- ✂ What does your child want to do?
- ✂ Who would your child like to spend time with?
- ✂ Are there places your child would like to go?
- ✂ Are there things your child would like to do?
- ✂ What do you want to remember about your child's last days?
- ✂ What can you do to make memories?
- ✂ How do you want to spend your child's last days?
- ✂ What do you and your family members agree about?
- ✂ How can you work with family members to do some of these things?

You are not alone in facing this challenge. Many families before you have had conflict in their child's last days. Some things other families did may be helpful for you. We have changed the names and ages of the patients, but the situations are real.

Janie

Janie was a 14-year-old girl whose disease had spread. She and her parents knew she had only a few weeks or days to live. However,

she wanted to go to summer camp with her friends. Knowing Janie might not survive camp, her mother struggled but let her go because this adventure was so important to Janie. Janie had a wonderful time at camp, and participated fully in most activities, including the "prom." She came home and died peacefully a few days later. Her mother remembered that it was one of the hardest choices she had ever made. But, she realized Janie needed to have this experience to reach some of her dreams, such as having a prom date.

Tommy

Tommy was a 4-year-old who had battled his cancer for 3 years. His doctor told Tommy's mother he did not have much time left to live. Tommy's parents were not together, and they had serious conflict in the past. However, Tommy loved his father and looked forward to time with him. When a wish trip was arranged, Tommy's mother invited his father along so Tommy and his father could share the experience.

Sam

Sam was a 22-year-old who had been in treatment since he was a teen. Shortly after he married, his illness returned and rapidly got worse. His parents had taken care of him over the years, and they disagreed with Sam's new wife about how to manage his care and time. Sam made an advanced care plan that let everyone know his wishes. He gave his wife responsibility for his care and treatment. This removed the source of conflict, supported his wife, and reassured his parents.

Cindy

Cindy was a 13-year-old girl with an aggressive tumor. Her parents were separated at the time of her diagnosis and argued over everything. Cindy wanted both of them with her during treatment. They came to the hospital with her and worked with the St. Jude social work and psychology staff to manage their problems. At first, this did not seem to work, but after some time, they were able to

solve problems and compromise. Both of Cindy's parents stayed with her during her treatment at St. Jude and at home. Later, they reunited.

Johnny

Johnny was a 16-year-old boy whose father had given up everything to care for him while he was sick. Johnny's parents were divorced, and his mother had limited contact with him during his treatment. When Johnny had only a little time left, he asked to spend time with his mother, and she did come to be with him. Even though he was angry with Johnny's mother, his father lived with her in St. Jude housing. He let Johnny and his mother spend time together so Johnny could forgive his mother for not being there while he was sick, and talk about other issues with her.

When things don't work out well

Resolving family conflict is important for the dying child and family. Here are some examples of what happened when family members could not work out their problems:

Billy

Billy was a 7-year-old boy whose parents were divorced. He had an aggressive tumor. His parents fought over every part of his care, including who would have medical information, who would come with him to appointments, and who would spend time with him. When Billy had hospice care in his caregiving parent's home, the parent who did not have custody had to get a court order to visit Billy.

Suzie

Suzie was a 16-year-old girl whose parents had a bitter divorce. The effects of Suzie's tumor and treatment made her too sick to care for herself, and she needed help with her personal care. She was more comfortable with her mother providing this care, but her father had legal custody of Suzie. Her mother had visitation rights and had done

a good job helping with Suzie's care at St. Jude. When Suzie stopped treatment and went home, she wanted to be with her mother because she was more comfortable with her mother's care. However, Suzie's father insisted on maintaining control of her care against Suzie's wishes.

Ideas to consider

If you have family conflict, consider some of these ways to help resolve it:

- ✂ Focus on what your child needs and wants.
- ✂ Look for ways to compromise.
- ✂ Talk with someone who is neutral and can help solve the conflict (friend, St. Jude staff member, or professional mediator).
- ✂ Try to put the past aside and think about what your child needs right now.
- ✂ Find ways to work together.
- ✂ Start with a small compromise, such as making a schedule for visiting your child.
- ✂ Recognize your grief and find people and activities to support you that don't add to the conflict.
- ✂ Think about where the anger and conflict come from. Are you angry at your child's illness and taking it out on your husband, wife, or other family member? This is not unusual during difficult times.
- ✂ Try to feel compassion for everyone, even in conflict.
- ✂ Talk to your family doctor (primary care physician) about your stress, and ask for help with family conflict.
- ✂ Make sure to take care of yourself (See next section: "Taking Care of Yourself").
- ✂ Use the support and counseling available from the St. Jude social work staff, chaplains, and psychologists.

Comment from a parent on emotions

The father of a child who was sick at St. Jude remembered how feeling frustrated and sad about his child’s illness turned into being angry with his wife and other people. He suggested that parents ask themselves, “Who am I mad at?” You might be angry at your child’s disease rather than your spouse or another person.

Legal issues

St. Jude does not take sides in custody and visitation disputes. We encourage you to work them out in the best interest of your child. However, if there is a court order for custody and visitation, we honor the court order.

Safety issues

St. Jude is committed to providing a safe, peaceful environment for patients, parents, and staff. We hope all families will be able to resolve conflicts on their own. We will work with families, staff, and hospital security as needed to ensure a safe environment.

Where to go for help

If you need help with family conflict, talk to a St. Jude social worker or chaplain, ask about talking to a psychologist, or talk to your child’s doctor or nurse. We are here to help you.

Notes:

Taking Care of Yourself

You might think taking care of yourself is not important, or that you cannot make yourself a priority right now. While you might spend most of your time and energy caring for your sick child, remember to take care of yourself, too. Keeping yourself as physically, mentally, and spiritually healthy as you can will help you take better care of your loved one.

It is hard to care for a sick child if you are not feeling well or you are too tired. In this section of the book, we will share personal care tips from other parents and St. Jude staff.

Your own body

- Remember to eat right and get enough sleep whenever you can. Not doing these things will only make you more tired and make it harder for you to give your child the attention you want to give. It can also make you more frustrated and emotional. Children notice when you are not taking care of yourself and may feel bad about it or might try to follow your example.
- Take breaks for baths, haircuts, laundry, shopping, etc.
- Get regular exercise whenever you can.

Take care of your own health. Go to doctor and dentist appointments and get regular eye care.

- When you feel tense, be aware of your breathing. Try this: Breathe in while counting “One ... two ... three ... four.” Hold your breath while counting to 7. Breathe out while you count to 8. Ask your child’s social worker or a St. Jude psychologist about other breathing exercises. Be aware of tense muscles. Do some slow careful neck stretches and stand up and stretch.
- Try some relaxation strategies such as progressive muscle relaxation or guided imagery (your social worker or psychologist can help).
- Whenever possible, rest or take a break when others want to help. A caregiver’s job is usually 24/7, but everyone needs a break now and then. It is OK to rest.

Your mind

- Write in a journal about your thoughts and feelings or talk to others who can encourage you.
- Focus on what is going OK each day, and remember to enjoy your child. Show your child a positive attitude. For

example, “OK, that didn’t work, but we are going to try something else.” Attitude is important in coping.

- ✂ You can still have hope during this difficult time. You might hope for a pain-free day or hope for a sibling to be able to visit. Find new ways to be hopeful.
- ✂ When you cannot have a positive attitude, be honest about your emotions. Showing your child you can manage even when you feel sad or angry is important.
- ✂ Ask for privacy or alone time when you and your family need it.
- ✂ Focus on your child’s care, not the illness. Thinking “why” or “what if” may only be hurtful.

One parent said, “I’ve heard some caregivers talk about the illness as if it were a person. If it were, they would kill it over and over again. This is understandable. However, letting the illness control your every thought will not change the problem. It controls you and your outlook and how you decide to live. I’m not saying that you won’t want to ask all the questions about “why your child” but dwelling on it will not help. As a mom who has also lost a child, I know that focusing completely on your problems puts you in a depressed state. You can’t think clearly, and it affects everything.”

These are other things that might help:

- ✂ Find time for humor—laughter heals the spirit. Allow yourself to see the lighter side of things and to laugh.
- ✂ Explore your own healthy distractions, such as reading, exercise, handiwork, crossword puzzles, etc.
- ✂ Many people find music soothing or energizing. Find times to de-stress with music.

Your social network

- ✂ Try to talk and maintain healthy relationships with those closest to you.
- ✂ Try to understand your partner and other family members and friends. Men and women grieve and handle situations differently, and that is OK.
- ✂ Think carefully about the right person to ask for advice or opinions.
- ✂ If friends or family offer to help, say yes. People really do want to help. Give them a choice of things to do to help. This gives them options, and lets you keep some control over who does what.
- ✂ Ask for help when you need it. Do not be afraid to call a friend, family member, or the St. Jude staff to ask for help. Asking for help does not mean you are not a good caregiver. It just means that you need help. Asking for help can also help the people who want to do something for you.

Your routines

- ✂ Live a normal life as much as possible.
- ✂ One mother whose daughter was at St. Jude said: “While caring for my daughter, I still had to take care of myself, my husband, and my other daughter. I tried to live as normal a life as possible by continuing to do activities that we enjoyed before our crisis. For me, I didn’t want to share my plight with everyone. I wanted just to be a family that was going through a difficult time. I didn’t want all conversations to be about our crisis. This is why I love sharing information through a Web site, because I could refer people there for an update instead of rehashing everything a hundred times a day.”
- ✂ There are many Web sites you can use to share your child’s story. Friends and family who want to know how she is

doing can go to the Web site to get updates. They can also leave messages for you and your child. If you use the Internet to share personal information, be careful about privacy. You might want to talk with your social worker.

- ✚ Plan outings away from the hospital or family housing.
- ✚ Keep up special daily routines with your child as much as you can. These can be meals in a quiet place with time for conversation, bedtime routines such as bubble baths, quiet time, or reading with your child.
- ✚ Think about new ways to celebrate holidays and other special days. You might want to keep up family traditions or create new ones. You can celebrate birthdays or special holidays on different days if that works better for you or your child.

Your spirituality

- ✚ Use prayer, meditation, or other spiritual practices to find meaning and strength.
- ✚ Maintain hope. What you hope for may change, but find a place for hope such as a good day, an outing, or being close to friends and family.

Even if you try to take good care of yourself, you may still feel stressed. You might find that talking with other people is especially comforting. If you are not sure about doing this because you do not want to burden other parents, your family members, or your friends, remember that the St. Jude staff can help, too. You can always ask your child's care team including your chaplain, social worker, child life specialist, or psychologist for support. We are here for you and want to help. Your social worker might help you find a support group in your area. Your local pastor, priest, rabbi, or other spiritual leader can also be helpful.

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Common Symptoms at the End of Life

Pain

You might be afraid that your child will have pain as she becomes sicker. She might be receiving some pain medicine already. Many different types of medicines can be used to control pain. If you think your child might have pain or discomfort, tell the doctor, nurse, or someone else on your child's care team.

These are some common signs of pain that your child may show:

- ☞ Being restless or agitated
- ☞ Stiffness
- ☞ Frowning, complaining, moaning, or crying more than usual
- ☞ Changes in sleep habits (sleeping less or more than usual)
- ☞ Refusing to eat
- ☞ Limp
- ☞ Not walking
- ☞ Not using an arm or leg

Preventing pain can help keep your child comfortable. These are some ways to help prevent pain:

- ☞ Give pain medicines as directed and call your child's doctor or nurse if pain seems to get worse or change. Your child's care team can adjust the pain medicine to help your child feel better.
- ☞ Keep your child as stress-free as you can.
- ☞ Use a special bed, such as a hospital bed, or equipment to help prevent pressure sores if your child has to stay in bed.
- ☞ Keep your child from getting thirsty or hungry.
- ☞ Use distractions like videos, games, and books.

These are some tips to help manage pain:

- ☞ Try to keep your child calm.
- ☞ Learn simple distraction and relaxation exercises to use with your child.
- ☞ Tell your child why she is hurting, so she is not afraid of something she does not understand.
- ☞ Follow the medication plan and call your child's doctor or nurse if the medicine is not keeping your child comfortable.

Getting tired easily

Fatigue (feeling tired) is the most common symptom children have at the end of life. It can be overwhelming to your child and your family. Your child may seem fine but not have any energy to do things.

Some common signs of fatigue include:

- ☞ Sleeping more;
- ☞ Being too tired to do normal activities;
- ☞ Having trouble thinking or concentrating; and
- ☞ Not being able to get out of bed.

You and your child want to make the most of the precious time she has left. To help manage fatigue, you can do the following:

- ☞ Make sure your child gets enough restful sleep. Try different rest or nap times during the day. Your child's doctor may prescribe a sleeping pill to help make sure your child sleeps at night.
- ☞ Make sure your child gets some physical activity each day, for as long as possible. This can give her more energy and help her sleep better.
- ☞ Plan daily activities to avoid rush and stress.

- ☞ Save up energy for what your child enjoys most, like special events or favorite activities.

Your child's care team can help treat problems that are adding to the fatigue. This could be low red blood cell count, medicines, a need for better nutrition, or the need for oxygen.

Sometimes treating emotional stress factors like depression and fear can make your child less tired. You might want to ask for a psychologist or child life specialist to see your child.

Fatigue is part of the dying process. You can have more times of holding and simply being together, enjoying quiet storytelling and remembering. Be available when your child does have energy and wants to talk or be active.

Emotional distress – feeling depressed, irritable, and anxious

It is normal for a child who knows she is very sick to have times when she is afraid.

These are some common symptoms of emotional distress:

- ☞ Anger – from irritation to rage
- ☞ Fear – from clinging and acting dependent to terror
- ☞ Sadness – from dullness to despair
- ☞ Withdrawal – from lack of interest to trouble concentrating to shutting out the world. Emotional withdrawal, being less interested in life in general, is a normal part of the dying process.
- ☞ Helplessness – from confusion to loss of control. If your child is toilet trained, she may wet the bed. If she has learned not to hit other children or adults, she may start hitting when she feels helpless or loses control.

- ✂ Eating or sleeping less or more

These are some ways to help your child in times of distress:

- ✂ A quiet environment may make her less irritable.
- ✂ Talking with a social worker or psychologist and doing relaxation exercises can help. Massage therapy might also be helpful.
- ✂ Your child might need to talk about her fear of dying but may not want to discuss it with family members. Social workers, psychologists, chaplains, and child life specialists can help.
- ✂ Treating pain or discomfort that might be causing the anxiety can be helpful.
- ✂ If possible, find a safe way to help your child express feelings with play, drawings, or storytelling.

Nausea and vomiting

Feeling “sick” is the way we often describe the feeling of nausea. This feeling can be upsetting.

Some common symptoms of nausea include:

- ✂ Gagging;
- ✂ Refusing fluids or foods;
- ✂ Acting restless or irritated; and
- ✂ More saliva or drooling than usual.

These are some tips to help prevent nausea and vomiting:

- ✂ Give your child anti-nausea medicines as planned by you and your child’s care team.

- ✂ Use anti-anxiety medicines and calming activities like massage to lower stress and anxiety.
- ✂ Laxatives and regular bowel movements will help avoid constipation, which can sometimes cause nausea.
- ✂ Give pain medicines the right way to prevent the nausea that comes from pain.
- ✂ Keep track of when your child has nausea and vomiting. This can help you and the care team make a plan to help prevent it. Write down when it happens, how long it lasts, if your child vomits, and what the vomit looks like. Write down what helps your child, and share this information with your child’s care team.
- ✂ Try to help ease coughing, which can make nausea worse.

These are some tips for managing nausea and vomiting:

- ✂ Plan your child’s foods carefully. Try bland foods. Avoid foods that smell very strong.
- ✂ Give anti-nausea medicines as prescribed by your child’s doctor.
- ✂ If your child is being fed by G-tube, stop the feeding and remove any of the formula that is in her stomach. After your child vomits, rinse her mouth with club soda or mouthwash (that does not contain alcohol).
- ✂ Help your child get as much fresh air as possible and encourage deep breathing.
- ✂ Use relaxation and distraction at the first signs of nausea.

Loss of appetite and weight loss

Feeding is an important way for you to show love to your child. But, if your child is very sick or has little energy to eat, food can be just another source of stress.

Signs that your child might not enjoy or need as much food include the following:

- ✎ Complaining that the food tastes funny
- ✎ Feeling sickness from the smell of many foods
- ✎ Eating just one or two types of food
- ✎ Not wanting favorite foods or drinks
- ✎ Getting tired after chewing and swallowing a bite or two

These are some tips on how to manage loss of appetite:

- ✎ Think about treatment that might help your child enjoy food again. Is she nauseated, depressed, or taking medicine that affects her interest in food?
- ✎ Offer small meals or snacks more often. Giving your child what she wants when she wants it can help.
- ✎ Think about ways to make eating fun.
 - Have a picnic on the bed.
 - Make pretty plates of food. Draw a face on a boiled egg, or cut sandwiches into shapes with a cookie cutter.
 - Give your child food that is easy to swallow and digest, like pudding. Ask your child's nurse or care team about foods that might be easy to eat.
- ✎ Consider food supplements such as Ensure® or Boost® if your child would rather drink than eat.
- ✎ Prevent thirst or dry mouth if your child stops drinking.
 - Keep her mouth clean and moist to keep her from getting thirsty.
 - Offer ice chips or popsicles.
- ✎ Treat mouth sores and use pain medicine if her mouth hurts.
- ✎ Remember that eating less is a natural part of the dying

process. Your child's body is using less food, so she will not want to eat as much as in the past. Allow your child to eat when she expresses a desire for food.

Sleep

Your child's sleep patterns may change. This is normal at the end of life.

- ✎ Your child may sleep during the day instead of at night.
- ✎ Your child might sleep less.
- ✎ Her sleep might be more restless.
- ✎ Your child may sleep more as death comes closer.

If your child has trouble sleeping, these are some things that can help:

- ✎ A night-light or open door might help her feel safe.
- ✎ Put a bell beside the bed that your child can ring if she wakes up.
- ✎ Move your child's bed into a room closer to family activities.
- ✎ Give your child a massage, a warm bath, or a shower before bedtime.
- ✎ Distractions like music, stories, and videos can be comforting.
- ✎ A loved one can sleep beside your child all night.
- ✎ Your child's doctor can prescribe medicine if none of these tips help.

Make sure your child is safe in her bed so you can sleep restfully.

If your child is sleeping most of the time:

- ✎ Try to have family times when your child is awake and alert; and

- ✂ Ask your child's doctor or nurse to review your child's medicine schedule to allow your child to be as awake as possible while still being comfortable.

Changes in breathing

Breathing problems are one of the most upsetting symptoms for family members. As your child gets close to the end of life, her breathing pattern may change. There are things the care team can do to help your child feel comfortable.

The risk of breathing problems is higher if your child:

- ✂ Has a disease that affects the lung;
- ✂ Has had many lung infections;
- ✂ Has fluid in the lungs or around the heart;
- ✂ Has problems with coughing or swallowing (which can cause stomach contents to accidentally get into the lungs);
- ✂ Is anxious, has pain, or has a low red blood cell count (anemia);
- ✂ Has pressure on the brain;
- ✂ Has an irregular breathing pattern; or
- ✂ Is not able to stay awake.

Signs that your child may be having trouble breathing include:

- ✂ Shortness of breath;
- ✂ Feeling dizzy or lightheaded;
- ✂ Less energy;
- ✂ Change in pulse, blood pressure, or the way she breathes;
- ✂ Gasping for air;
- ✂ Headaches in the morning;

- ✂ Blueness around the mouth or fingernails;
- ✂ Pain in the chest;
- ✂ Noisy or wet-sounding breaths;
- ✂ Coughing;
- ✂ Breathing really fast; or
- ✂ Irregular breathing.

These are some ways to help your child when breathing is difficult:

- ✂ Put your child in the position that is most comfortable for her.
- ✂ Ask your child's doctor about medicines, such as morphine, that can help control feelings of breathlessness or panic.
- ✂ Use oxygen if your child's care team has prescribed it and your child is having trouble breathing.
- ✂ Open a window or turn on a fan. Feeling the moving air can help your child feel less breathless.
- ✂ Remove tight clothing.
- ✂ Create a calm environment. Your panic can make your child more afraid.

As death comes closer, your child may breathe differently. She may gasp or take short breaths that do not seem to give her much air. This can be upsetting to watch, and your child may look uncomfortable. If your child's doctor has prescribed morphine, you can give it to her during these times. When your child breathes this way, it is probably very close to the time when she will die, and she is likely not in any discomfort from the breathing problems.

Decreased urine output

As your child's illness progresses, certain organs may start to shut down as the body tries to conserve energy. As the body comes closer to death, the organs that often stop working first are the kidneys.

If your child starts to produce less urine, this is a sign that her kidneys are starting to shut down.

The body needs much less fluid (liquid) when it is dying. This will also cause your child to produce less urine.

Your child's doctor may treat decreased urine output by giving her IV fluids or having her drink more water. What you decide to do will depend on the goals of care you and your child decided on and the reason for decreased urine. Please discuss this openly with your child's doctor.

Changes in bowel function

Constipation

Constipation is common in children near the end of life. The risk of constipation increases if your child:

- ✎ Is not eating or drinking as much;
- ✎ Is not getting out of bed very much;
- ✎ Is taking strong pain medicines; or
- ✎ Has a tumor that blocks her bowel or affects the nerves that help the bowels empty.

These are some common signs of constipation:

- ✎ Fewer or hard bowel movements
- ✎ Bloating abdomen (stomach)
- ✎ Stomachache or cramps

- ✎ Hard stools or straining on the toilet
- ✎ Stool or blood smears on the underwear or sheets
- ✎ Vomiting

It is very important to keep your child's bowel habits regular, because preventing severe constipation is much easier than treating it.

The following are tips for managing constipation:

- ✎ Encourage your child to drink fluids.
- ✎ Add natural laxatives like high fiber into meals and snacks.
- ✎ Keep your child as active as possible.
- ✎ Give your child a stool softener regularly, unless she has diarrhea.
- ✎ Give prescribed medicines for relief of constipation.

Your child's doctor, nurse, or another member of the care team can help you decide:

- ✎ If she needs medicine for constipation,
- ✎ If changing her diet or activity may help, or
- ✎ If there are other things you can do.

Diarrhea

Diarrhea (loose stools) can be hard to cope with because they can cause your child to have accidents. Diarrhea is more common when your child:

- ✎ Has an infection;
- ✎ Has had abdominal radiation;
- ✎ Is stressed;

- ☞ Takes medicines that make the bowels more active, like some chemotherapy or antibiotics;
- ☞ Takes too much anti-constipation medicine;
- ☞ Has a disease that affects how the bowels work and it is getting worse; and
- ☞ Has been constipated and the waste has formed a hard clump. This creates a block in the bowel and some watery stool leaks around it.

The following are tips for preventing and managing diarrhea:

- ☞ Check with your child's doctor or nurse to see if your child's medicines or treatments could be causing the diarrhea.
- ☞ Treat an infection that is causing diarrhea.
- ☞ Change a medicine that is causing diarrhea, give your child less medicine or stop the medicine.
- ☞ Stop giving foods or nutritional supplements that cause diarrhea, or mix them with water or other food so your child does not get as much.
- ☞ Check with your doctor or nurse before giving medicines to stop diarrhea.
- ☞ Keep your child's skin clean.
- ☞ Prevent your child from becoming constipated.
- ☞ Check your child's bottom often for signs of redness, swelling, or pain.
- ☞ Provide comfort and dignity by offering your child privacy. Keep her clean by using blue pads or diapers to avoid staining sheets.

If you are concerned about any changes in your child's bowel movements, talk to the care team. You can help by taking note of how often your child has a bowel movement and how much stool she

normally makes. You can also note the color of the stool and whether there is blood or mucus in it.

Fever

As your child's illness progresses, she may develop a fever. While this is usually not dangerous, it can make your child uncomfortable. Your child is more likely to have a fever when she:

- ☞ Has an infection anywhere in the body;
- ☞ Is taking a medicine that causes fever;
- ☞ Is drinking very little and becoming dehydrated;
- ☞ Has a condition that affects the part of the brain that controls body temperature;
- ☞ Has a disease that affects the blood cells that are part of the immune system; or
- ☞ Has tubes in her body like a G-tube or IV line.

How your child's doctor treats her fever will depend on the goals of care you and your child decided on. If the fever is new, make sure to tell your child's care team.

These are tips for managing fever:

- ☞ Help bring the fever down and make your child more comfortable.
 - Wash your child's face with a cool cloth.
 - Dress your child in light clothes or cover her with a light blanket.
 - Cool the room.
 - Bathe your child in lukewarm (not cold) water.
 - Use cool water bottles.

- Encourage sips of cool drinks.
 - Check with your child's doctor about using medicine to reduce fever.
 - Change bed linens if they are damp with sweat.
 - Keep your child's lips moist and clean.
 - Reassure and calm your child.
- ☞ Treat the underlying cause.
- Antibiotics may or may not be appropriate if an infection is present. Your child's doctor or care team can talk with you about this.
 - If the fever is causing your child to be uncomfortable, talk with the care team about stopping any medicines that are causing it.

Losing bowel and bladder control

Your child may lose control of her bowel movements and bladder (urination) as the illness progresses. This is common. There may be a physical cause, or your child may be going back to an earlier time in her development before toilet training.

Some causes for losing bowel and bladder control include:

- ☞ Infection;
- ☞ Disease progressing; and
- ☞ Spinal cord or nerve problems.

It is important to tell your child's care team if your child loses bowel or bladder control, as this may be something we can treat.

Seizures

A seizure causes uncontrolled body movements. If your child has a seizure, she may lose consciousness (pass out). Seizures can be

frightening to watch but usually are not dangerous. Seizures do not cause brain damage unless they go on for more than 30 minutes. Your child is more likely to have a seizure if she:

- ☞ Has pressure on the brain from fluid building up or from a growing tumor;
- ☞ Has a high fever that cannot be controlled;
- ☞ Is not taking enough anti-seizure medicine or cannot take prescribed medicines; or
- ☞ Has a condition that causes seizures, and that condition is getting worse.

Signs of a seizure can include:

- ☞ A blank stare;
- ☞ Suddenly turning blue around the mouth;
- ☞ Twitches of any body part (eye, hand, tongue, foot);
- ☞ Large jerky movements of the head, arms, and legs; and
- ☞ Strange feelings, sounds, or sights. This is called an "aura," and some children have this before a seizure.

If your child has a seizure, she may be very sleepy after it is over. This is normal after a seizure.

These are tips for preventing seizures:

- ☞ Give medicines prescribed to control seizures.
- ☞ Treat fevers quickly.
- ☞ Avoid anything you know causes your child to have seizures.

The following are some guidelines for what to do if your child has a seizure:

- ☞ Lay your child down to protect her from falling or getting hurt during the seizure.
- ☞ Turn your child's head to the side.
- ☞ Do not put anything in your child's mouth.
- ☞ Stay with your child.
- ☞ Be sure you know how and when to give any emergency medicine if a seizure lasts longer than a few minutes.
- ☞ Comfort your child when the seizure is over.
- ☞ If your child has not had a seizure before, tell your care team. The seizure may mean a change in the way your child's brain is working.

Have a plan in place for how to manage a seizure. Your child's care team can help you plan so you know what to do. There are many medicines that can help control seizures. Talk with your child's doctor or care team about medicines that might help your child.

Confusion and other mental changes

If your child is confused, she may have trouble putting thoughts together in a way that makes sense. Confusion usually has more than one cause. Being anxious, uncomfortable, afraid, or in pain can make your child more confused. Being in a strange place with strange caregivers can also make confusion worse.

If your child is confused, try following these guidelines:

- ☞ Remind your child often who she is, where she is, and that you are with her.
- ☞ Accept what your child claims to see and hear. Try not to correct or explain away what she says, but tell her that she is safe.
- ☞ Think about what makes your child feel quiet and relaxed.

It might be staying in a room with family members or being alone in a quiet room.

- ☞ If your child is restless or picking at things, do not hold her down unless she is in physical danger.
- ☞ Talk to your child's care team about medicines that can help if your child seems afraid or anxious. These medicines may calm her down. If your child is afraid to go to sleep because of bad dreams, medicine may help her get some rest.

As death comes closer, your child may be confused more often. She may go into a coma and not respond to you or other people. Keep talking to your child, and tell her you love and care about her and will stay with her. Hearing is usually the last sense lost when a person dies.

Notes: _____



Hospice

Hospice is a service that helps keep your child physically, emotionally, and spiritually comfortable at the end of life. Your child can have hospice care at home, in the hospital, or in a hospice facility. A hospice care team includes a doctor, nurse, social worker, chaplain, and other care providers, such as nursing assistants.

Receiving hospice care means you can make fewer trips to the doctor's office or hospital. Your hospice team will still coordinate your child's care with her primary care team at St. Jude.

Hospice also can help you and other family members, including your child's brothers and sisters, grandparents, and other close relatives. A hospice worker will visit your child and talk with you and your child's primary doctor to decide what kind of care your child needs. If your child's needs change, the hospice worker can help you make a new plan.

You may want your child to have hospice care at home, so she can be in a familiar and comforting place, see friends and do favorite activities. It can also be easier for family and friends to visit your child at home.

Your hospice care team will support you after your child dies. Hospice workers can provide grief counseling.

Frequently asked questions about hospice

Is hospice right for our child?

Talk with your child's doctor and primary care team about the medical care your child needs. Consider what is important to you and your child and think about other support you might have at home or in your community. Your child's doctor and care team can help you decide if hospice is right for you and your child.

How would we find a hospice service?

Your child's care team can ask a clinical nurse specialist to help find hospice care in your community.

Should we wait for our doctor to mention hospice?

Your child's doctor may tell you about hospice, or you may ask a doctor, nurse, social worker, or other member of your child's care team if hospice is right for your child.

Can we still bring our child back to St. Jude for clinic visits if we want?

Yes. The doors of St. Jude are always open to you and your child. The plan will be flexible to your child's needs. If she has a hard time coming to St. Jude, the care can be provided in the home through hospice.

What if we feel hospice is not working for our child?

You should always stay in contact with your primary team at St. Jude. If there are problems, let us know, and we can work with hospice to fix any issue.

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If Your Child is Dying

Some things to consider

If your child is receiving care for comfort instead of to cure her disease, the care team has probably talked with you about what is most important to you now. You may have also talked about the following:

- ✧ What treatments and procedures you want and don't want for your child
- ✧ Where you want your child to receive care
- ✧ Things your child wants to do soon
- ✧ How you want to spend time with your child and other family members

While your child's care team can discuss these thoughts with you, you and your child will make these decisions.

Creating a comfortable environment for your child

If you choose to keep your child in the hospital, or if she needs to stay there, you can still arrange the room to make it comfortable and pleasant. The St. Jude nurses and child life specialists can help you make the room more personal with drawings on the window, artwork on display, favorite blankets, favorite music, videos, and toys.

If you take your child home, you can work with your family and with hospice staff, if they are involved, to create comfort. You may want to move your child's room to a more comfortable place in the house, such as a den or living room. This room might be closer to you, or easier for other family members to spend time with your child. You can decorate this room with some of your child's favorite things.

Time together

If your child is in the hospital, you can talk with the nurses about how you can help with your child's care. There may be things you want to do for your child, things the nursing staff will need to do, and things they can do for you. If you are at home and using hospice services, talk with the hospice staff about how much help you would like with your child's care. Whether your child is at home or in the hospital, your child's care team can help you make your child comfortable with medicine and other treatments. You and your child can decide who is with you.

Talking to your child

By now, you know how your child handles information about her illness and what she prefers. Your child may be open and comfortable with talking and asking questions and wants to know everything. Or, your child may be quiet and depend on you to take care of her without giving many details about her illness. You know your child and her emotional needs best, but you may want to consider some things we have learned about children facing death. Even children as young as 2 have some understanding of death.

Children are more aware of their condition than adults may realize. If your child does not get direct information about her condition, she will gather information by watching and listening. She may notice changes in her body, changes in your behavior or moods, different medical routines and staff, more visitors, and family members or friends who are upset. She might also hear comments you think she does not hear. Without accurate information, your child will probably create her own version of what is happening to her. If this happens, she may feel alone, afraid, or sad, and you may not know about it or be able to comfort her.

Other parents whose children have died say you may need to help your child let go of life. This might mean telling your child it is OK to let go. The section on "How to talk to your child and others" provides

suggestions for talking with children of different ages. If you want help talking with your child now, a child life specialist, social worker, chaplain, or your child's doctor can help. If your child is receiving care at home, hospice staff can help you. If you do not have hospice, your child's hospital care team can help.

Creating memories

If your child can do projects or tell stories, you may want to use your time together to honor your child's legacy and create memories. Looking at family photos and telling favorite stories are some ways you can tell your child what she means to your family and how you will remember her. Arts and crafts projects and writing projects allow you to share feelings with each other and create memories. You can do these activities wherever your child is receiving care. If your child is in the hospital, your child life specialist, social worker, chaplain, and hospital teacher (if your child is school age) can help. If you are at home, family, friends, teachers, coaches, and other people your child likes can be involved. If you are home and are working with hospice, the hospice staff can also help.

Enjoying visitors

Depending on your child's preferences and how she is feeling, visitors of all ages are encouraged. Friends from school, family, and teachers may provide good support, activity, and a chance to share favorite stories and memories.

Remember that having many visitors your child does not know well may frighten her. It might make her wonder what is happening, especially if your child does not know how sick she is. If you are expecting visitors who have not seen your child in a while, tell them in advance about any physical changes in your child so no one (including your child) is surprised or upset. If your child is in the hospital, your social worker or child life specialist can help you with talking to visitors.

Be careful that your child does not have so many visitors that it is overwhelming. If your child is in the hospital, the nursing staff, child life staff, or social worker can help you make a plan to avoid having too many visitors at one time. If you are at home and using hospice, their staff can help you make a visiting plan. If you are not using hospice, talk to your child's care team about how to manage visitors.

Special outings

Some children feel well enough to ask to go to a movie, on a special shopping spree, home or to hospital lodging, or someplace else that is important to them. If your child is in the hospital, ask the care team about this. Depending on how your child is doing, she may be able to go out on a pass.

Caring for yourself

You may be afraid to leave your child for even a few minutes. We encourage you to take breaks, eat regular meals, and get some rest. If your child is comfortable with other family members or friends, let them give you a break. This will give them some special time with your child, too. If your child is in the hospital and you are alone with your child, talk to the care team about volunteers and assistants who can sit with your child while you take a brief break. Your child may worry about how you are doing, so taking time for yourself can actually reassure your child. (See section called "Taking Care of Yourself" in this book.)

You may also worry that your child will die when you are away from her room or when you are asleep. Many children have seemed to wait until a certain family member was present—or absent—to die. One mother, whose child died in his sleep while the whole family was sleeping, said later that this was the best thing for all of them.

How will we know death is approaching?

You may notice changes in your child's breathing. She may sleep more, eat less, talk less, or talk more. Each child is different, and your hospital care team or your hospice team will help you with this. You might also want to read the section on "Common Symptoms at the End of Life" for more details.

What should I do when my child is dying?

During your child's illness, you have learned what is comforting to her. You can simply stay with your child, using the things you know to help your child by talking, holding, comforting, soothing, singing, praying, and playing favorite music. You know best what is meaningful and comforting to your child. Your child may also let you know what she wants. You may want to have certain family members in the room with you or not, depending on what will be most helpful for you and your child. You may want spiritual support from your spiritual leader or a hospital chaplain, or not—again, whatever is right for your child and your family. You might want medical, nursing, or other staff there, or you may want privacy.

It is most important to do what is most helpful to your child and family. If your child is in the hospital, your care team will help you do what is best for your child and you. If your child is at home, your family and hospice staff can help (if you are using hospice). You may want to think about what activities, things, or people are most comforting to your child, and talk to your family and care team about this ahead of time.

At the time of death

If your child dies in the hospital, you and your family will be able to have private time together. If there are any religious practices that need to be done at the time of death, we will help you in any way we can. Let your child's doctor, nurse, social worker, chaplain, or child life specialist know about this ahead of time if you can.

After you spend some time with your child, the nursing staff will bathe and dress your child's body. You may help with this as much as you wish or allow staff to take care of this. If there are religious practices related to bathing, we will honor them.

There is paperwork that you will need to fill out after your child dies. A staff member will ask you whether you want an autopsy. All hospitals need to ask if you would like to donate your child's organs. What you decide needs to be put in writing by our medical staff. We also need to know your choice of funeral home and have your written permission to release your child's body to the funeral home. Your child's doctor or another staff person will review these forms with you along with your nurse, social worker, or chaplain. When you are ready, nursing staff will contact the local funeral home to have your child's body taken there. If you do not live in the Memphis area, St. Jude can help you find a funeral home that will help send your child's body home. The hospital also will help with the cost of transporting your child's body back home if you are not a local family. Your social worker can give you more information. You might also want to look at the section on "Planning a Funeral or Memorial Service" in this book.

If your child is at home, hospice staff will help you do the things described above. If you do not have hospice, talk to your child's care team about what to expect and what you might need to do.

Leaving the hospital, returning to housing, and going home

After your child dies, you may find it hard to leave the hospital. You and your family can take the time you need before leaving, and your care team will help you with this. Some families have been in the hospital with their child for weeks or even months. Family, friends, and St. Jude staff can help you with packing.

If you have been staying in hospital housing, we will tell the St. Jude housing staff that your child has died, so they can help

with your needs. Let them know if they can help. They can find boxes for packing to go home, help visitors find you, and help you decide when to leave housing. Your social worker and the manager of your housing facility can help you with housing policy, and let you know how soon you will need to go home. Your social worker can also tell you about hospital policy for travel assistance. Please let your social worker know if you expect problems or delays in returning home.

If your child dies in hospital housing

Your child may receive end of life care in hospital housing. If this happens, you will have a clear plan of support from your child's care team—your child's doctor, nurse, social worker, housing representatives, and other members of the team. This may include plans for when to come to the hospital, home health visits, and hospice care. It also will include a plan for what to do when your child dies, depending on what you and your child need.

You have probably noticed the word "hospice" several times in this section. You may want to read the section about "Hospice" for more details.

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When Hope Changes

When your child was first found to have a serious illness, you hoped for a cure. You may have expected proven medicines and treatments to cure your child's disease. Or you may have known that the current medicines and treatments might not be enough.

If your child is seriously ill, you might hear words that make you hope for something different. Your child's doctor might say:

- ∞* We are seeing no benefit from treatment. We've tried everything we know.
- ∞* Cure will no longer be our goal for treatment.

You might have heard similar words from your child's primary care team. These things are hard to say and hard to hear. They can make you question your spiritual beliefs, even things you have believed for a long time.

This section of the resource book can help you think about your spiritual beliefs and some of the questions parents and caregivers have when their children are dying. As you cope with painful thoughts and feelings, you might also find new reasons for hope.

Common spiritual questions

Below are some of the most common spiritual questions parents ask, and some thoughts that might help you. If you have questions or concerns, or want to talk with someone, you may call on a St. Jude chaplain. The chaplains are always here to help you.

Why did this happen to us?

No one knows exactly why children get serious illnesses. We do know that your child's disease was not caused by anything another person said or did. It also was not caused by anything special about your family, such as following religious traditions or not, having a divorce in the family or being close and loving. Cancer and other serious diseases happen in many different families, and a person can have a serious disease at any age.

Is God punishing me for something I did or did not do?

You or your child may believe God is causing your child to die. Although some people believe God does cause pain, suffering, and death, many also believe God gives:

- ✚ Love that never stops,
- ✚ Mercy for people who are hurting,
- ✚ Caring in times of anxiety and sadness,
- ✚ Strength for daily struggles,
- ✚ Peace for your troubled heart, and,
- ✚ Many other gifts.

You can choose to think about God in a way that gives you comfort instead of making you sad and anxious.

When you are no longer hoping for a cure, you can trust that God will always love and care for you and your child, no matter what happens.

Why didn't our prayers work?

If your child is dying, or has died, you might think it was a waste of time to ask God to help your child. You might also wonder if you prayed the wrong way or did not have enough faith to make the prayers work. You might even think that God chose to ignore you when you were hurting.

You might want to think about prayer in a new way. It is always good to be honest with God when you pray about things you want or need to happen. But, prayer can also be a way to feel God's love and presence. Knowing God is with you can help you cope with your child's illness. Because prayer is a relationship with God, you might have fears, doubts, and frustrations when you pray, just as you do in other relationships.

Sometimes you might not want to pray or feel as if you cannot pray. This could happen even if you have prayed many times in the past. It can be hard to pray when you are trying to tell God how sad or anxious you feel. This is normal for parents in difficult times. You can ask a friend, family member, or religious leader to pray with you and to pray for you at other times.

If you would like to talk to someone about prayer or different ways to pray, you can talk to a St. Jude chaplain or a religious leader near your home.

How do I handle my anger?

If you are angry, you might feel guilty. Remember that all your feelings are your natural response to losing your child. There really is no way to hide from these feelings, though many people try.

Talk to a caring friend or religious leader who will respect your feelings and listen without judging you. This is hard, but it can help to talk about your feelings instead of hiding them. If you are angry with God, you can talk about this with a trusted religious leader. You can also tell God in prayer. God is strong enough to handle your anger and understands your feelings more than anyone else.

What do I say to people whose comments hurt my feelings, make me angry, or are not helpful?

Some people who are trying to comfort you will say things that may upset you. These can include comments like the following:

- ✚ God will not give you more than you can handle. (Yet, you feel completely overwhelmed.)
- ✚ Your child is going to a better place. (But, you feel the best place for your child is with you.)
- ✚ God is keeping you from pain in the future. (You cannot imagine hurting more than you do now.)

Remember: You do not have to explain how you feel to anyone. You do not have to agree with what they say. It is most important for you to spend time with your child, to care for your child, and to grieve in a way that is natural for you. If someone makes a comment that upsets you, you can say, “I appreciate that you are concerned about us,” or “We are just thinking about what our child needs right now.”

Can I still believe in miracles?

Yes, you can still believe in miracles and any other spiritual ideas that are important to you. This does not mean you are being unrealistic. It means you still find hope in this part of your faith.

How do we handle this loss with other family members?

If your child is dying or will soon die, other children will probably have questions and fears. Younger children might wonder if their thoughts, actions, or feelings could have made your child sick. If they are told that God took your sick child to heaven, they may be afraid God will also take them. Because they are so sad, they might think that God has stopped loving them.

Children need to know that they are safe and that adults will keep taking care of them. You can tell them that God’s love for them does not stop. You also can remind them that their sister or brother is dying, or has died, because of a sickness that medicine and treatments could not cure, but that they do not have the same sickness.

Ask your children what kind of questions or thoughts they are having. Answer their questions honestly and simply, if you can. It is fine to say that many things are a mystery to us and to tell them when you do not have answers.

Share your own spiritual beliefs and traditions about death. For example, if you believe in heaven, tell your children about this. It is important to be honest about what we do not know. It is OK to say, “We do not know exactly what heaven is like, but we believe it is a

good place where we are not alone, where we are safe, and where we are not sick anymore.”

Share your own feelings. Tell your children if you feel sad, angry, or afraid. It helps children to know that you have the same kinds of feelings they do.

Since you may be very tired, spiritually and physically, let other adults help your children. Your religious leader, relatives, and family friends can help care for your children at this difficult time.

Spiritual affirmations

Writing a list of your spiritual beliefs can be helpful in difficult times. When you feel sad or angry, you can look at the list to remember what you believe. When you learn something new, you can add it to the list.

These spiritual thoughts might help:

- ✚ God has helped you care for your child during a serious illness. A few years ago, you might not have known you could do this. You might not have always felt God’s presence, but God still helped you. God will continue helping you care for your child at the end of life.
- ✚ You can make choices to help your child die with security, dignity, and respect. Making these choices is an important part of taking care of the person God gave you when your child was born.
- ✚ Your spiritual beliefs are part of this difficult time. You can make sure these beliefs are respected by the people who care for your child. You can trust your own spiritual wisdom, and ask for things that add meaning to the end of your child’s life. These could be special prayers, music, anointing, candles, or other things from your faith. At the end of

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What is an Autopsy?

An autopsy is a medical exam of the body after a person has died.

Hospital staff may ask you to give permission for an autopsy on your child, or you may ask for one. Asking permission for an autopsy is standard medical practice in the United States.

The purpose of an autopsy is to help answer questions about the illness and cause of death. It also might give doctors information that helps them understand disease, find new treatments, or treat other children.

What can be learned from an autopsy?

An autopsy can tell doctors more about your child's illness and how it was treated. Sometimes, a child's death is caused partly by genes or the environment. Having this information might help other family members stay healthier. An autopsy does not guarantee doctors will know everything about your child's death, but it may provide some answers. If you have specific questions you hope the autopsy will answer, be sure to tell your child's doctor beforehand.

What are other benefits of an autopsy?

The autopsy might be comforting if it helps you understand the causes of your child's illness and death. It can also show that doctors provided the right treatment for your child. This might make you feel less guilty about your child's death and keep you from wondering if you made the right decisions about treatment. Giving permission for an autopsy allows you to take part in medical education and research that might help other current or future patients.

Who can request an autopsy?

You can request an autopsy if you are the patient's mother, father, adult brother or sister, husband or wife, or if you are legally in charge of the patient. Before the autopsy, hospital staff will ask you to sign a consent form that says you agree to the exam. On the consent form, you can tell hospital staff if you want the doctor to look at certain areas of the body but not others. For example, the autopsy could be done on only one area of the body, such as the brain. You can also tell the hospital if they may keep tissue to examine it later. The only time anyone can do an autopsy without your permission is when doctors are not sure why the patient died. In that case, a doctor called a coroner would examine the body to find the cause of death.

How is an autopsy done?

An autopsy is done by a specially trained doctor called a pathologist. This doctor looks at the body to find clues about why the person died. The organs inside the body are examined, and samples are looked at under a microscope. Normally, the hospital keeps the organs so doctors can learn more by studying them later. If you do not want the hospital to do this, you can write on the consent form that the organs should be returned to the body. An autopsy is done in a room like an operating room, and usually takes 2 to 4 hours. The doctor who does the autopsy will treat your child's body with dignity and respect, just as in a medical exam or surgery. St. Jude staff will make sure your child's body is well cared for until it goes to the funeral home.

Can a limited autopsy be done?

It may be possible for a limited medical exam to be done if you do not want a full autopsy performed on your child. A limited autopsy focuses on a certain area of the body or on a certain body system. The pathologist can collect small tissue or fluid samples, such as those collected with a needle biopsy. The doctor will still ask your permission to collect a smaller sample and you may state any restrictions, limitations, or special requests.

Is there a way for a child's tumor or organs to be used after the child dies?

Sometimes there is the option to donate your child's tumor for research purposes through a research-related autopsy study. Also, children with some types of progressive cancer can donate their corneas from their eyes to help other people see better. Donating the corneas or the tumor through an autopsy could cause a minor delay in the body being ready for the funeral home, but it should not affect the type of service you plan (such as an open casket or closed casket service). These are difficult decisions, so please speak with your care team if you would like to know more about donating your child's tumor or organs.

Can we still have a funeral or a memorial service?

You can still have a funeral with burial or cremation, including an open casket funeral. When the autopsy is done, the hospital will contact the funeral home to care for the body. After the funeral home cares for and dresses your child's body, you will not be able to see that an autopsy was done. If you plan a burial soon after your child dies, you can still have an autopsy. Hospital staff will arrange to do the autopsy sooner. If you have questions about this, talk to your child's doctor or social worker.

How much does an autopsy cost?

If the autopsy is done at St. Jude, there is no charge. If a child dies at home or in another hospital, you will need to talk with your care team at home about the cost.

When will we know the autopsy results?

The first autopsy results are usually ready in 2 to 3 days. Because complex tests are done on some of the tissue samples, final results may take several weeks. Within a month after the final report is complete, you will have a chance to talk about the results with hospital staff. It is usually best to meet in person, but you may also learn the final results by telephone. We will give you the final results of the autopsy and any tests, and do our best to answer your questions. We also will tell your child's doctors, nurses, and other staff what the autopsy showed so they can learn from the results.

What if I have questions?

Your child's doctor can answer your questions about an autopsy and talk with you about your concerns. The nurses, your social worker, your chaplain, and the child life staff are also here to help you decide about an autopsy and to support you at this difficult time.

Notes:

Planning a Funeral or Memorial Service

During your child's illness, you have faced many difficult situations. Planning a funeral or memorial service for your child is something most parents think they will never have to do.

At the end of your child's life, you may have questions about these services. We will try to answer some of the most common questions here.

What is the purpose of a funeral, memorial service, or life celebration?

Funerals and other services are for the living, not the person who has died. These services bring family and friends together to honor a loved one's life and contributions, to share grief, and to give support and comfort.

How do we plan a service?

Start by thinking about your child and family. What is unique about your child? What are her talents or interests? Things your child loves, such as music, animals, or colors? Are there things your child does not like, such as getting dressed up? What special places does your child love? What spiritual and family traditions might be part of the service? Think about what will give you comfort and support. Some families prefer a traditional funeral service, and other families would rather have something different.

Who should help plan the service?

Your social worker, your chaplain or a trusted family member or friend can help you with finding information and planning. This person can stay calm and help you make decisions. Having someone to help can allow you to spend more time with your child.

You might want your child to help plan the service, or your child might ask to be involved. Children sometimes have strong ideas about what they do and do not want. For example, one 12-year-old boy helped plan his celebration service. He asked his friends and family to wear casual clothes because he hated to dress up. He chose the music he wanted, and planned a barbecue afterwards because he loved barbecue. An 11-year-old girl told her family how to live and what to remember about her life. A 20-year-old girl left instructions on the music and people who would speak at her service and how she wanted her makeup done.

Planning ahead can help you think things through at your own pace, so you can make thoughtful choices.

How can I get my child involved?

Your child might talk about funerals or ask about plans for a memorial service. You could also talk with your child in a gentle way, talking about other family members first. For example, one family told us how they talked to their daughter about funeral planning. They talked with her about grandma and grandpa and plans for their death. Next, they told her what they would want for their own services. Eventually, the daughter told them what she would like.

If your child is in the hospital, you might want to discuss other ways to talk to your child with your social worker, child life specialist, or chaplain. If you are at home with your child and using hospice, you might want to talk with hospice staff.

How do we choose a funeral home?

You might already know about a funeral home if you have been there for a service or they have cared for someone else in your family. This can be one of the places you consider when you decide who will care for your child. A friend or family member who is calm and supportive can help you find information on different funeral homes and make a good decision. It might also help to ask family members or friends about their experiences with funeral homes. It is important for the funeral home to have staff who will support you and work with you to create the service you want.

Here are some other questions to consider:

- ☞ Are there spiritual traditions and rituals that need to be followed?
- ☞ Do you want burial, cremation, or organ donation? Some children want to donate their bodies to help others.

- ☞ Where should we have the service? Church, funeral home, community facility such as a school auditorium, graveside, or a place your child loved?
- ☞ When is the best time to have the service? You may have spiritual practices that need to take place at a certain time. You might also need time for loved ones to travel to the service.
- ☞ Who should be part of the service? Clergy, family members, friends, representatives of the school or other groups your child belonged to, musicians?

Your social worker, chaplain, and child life specialist can help you think about what you need. Your social worker can also help you work with funeral homes and give you information on how to take your child's body home if your child dies at St. Jude or in St. Jude housing.

Helpful Web sites

www.funeralplanning101.com
www.funeralplan.com

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Afterwards

A few words about grief

Other families whose children have died at St. Jude have told us it can be very hard to leave the hospital and hospital housing. It never feels right, and it is not what you expected when you first came here. You might remember that when your child was first diagnosed, you and your family felt grief about your child's illness and its effect on the whole family. At times, the grief would come and go. You probably felt the shock, anger, sadness, and fatigue, and still did what was important for your child, your family, and yourself.

The grieving will continue, and it will come and go, with some days and times worse or better than others. You will also notice that each family member grieves differently and at a different pace. It is important to remember that family members might have different needs and ways of coping.

Some families find support and comfort from family, friends, spiritual leaders, and groups. Some families find grief counseling and grief support groups to be helpful. Some parents say books and pamphlets are helpful. These have ideas on handling grief, coping with children's grief, dealing with anniversaries, talking with friends, family, and other people, and finding meaning in life after your child dies.

The St. Jude staff will give you a packet of information. Your social worker, chaplain, and child life specialist can tell you about other things that might help. Your social worker can also help you find resources in your home community, such as support groups, counseling, and information.

Keeping in touch

The relationships you form when your child is at St. Jude can be very strong. The care team and St. Jude staff can start to feel like family, and it can be hard to suddenly part from the team. You might want to keep in touch with phone calls and visits. Please know that

these are welcome. If there are certain people you want to see when you visit, you might want to call ahead to see if they will be at the hospital that day.

Every year, St. Jude has a Day of Remembrance for children who have died in the last two years. We will send you information about that after you go home, and again before the Day of Remembrance happens. You are invited to come back for the weekend. There is a reception on Friday and a day of remembering with talks, workshops, lunch, and a memorial service on Saturday. Siblings can be with other siblings and express their feelings through activities. Your chaplain or social worker can tell you more about this special event.

Members of your care team, such as your child’s doctor, nurse, social worker, chaplain, or child life specialist will call you from time to time. If you do not want to keep in contact with St. Jude staff, please tell your chaplain or your social worker. Everyone grieves differently, and we will respect your wishes. Please know that the St. Jude staff care about your family, and we will be here to help you if you need us.

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