



# PARENTING A CHILD WITH A LIFE-LIMITING ILLNESS

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# PARENTING A CHILD WITH A LIFE-LIMITING ILLNESS



## Introduction

Learning that your child has a life-limiting illness can be devastating. After learning the typical prognosis for the disease, it is not unusual to worry about the future and anticipate what's to come. But with a slowly regressing illness, there is a lot of time to understand what you will need medically and emotionally. There will be time to connect with others and gain support; there will be time to explore treatment methods.

With a lot to learn, we hope this toolkit will serve as a helpful starting off point. Please be sure to check out all of the toolkit's components (the resource guide and the short videos) to learn more!

# SECTION 1: PRESERVING THE FAMILY



## Caring for Siblings

“Siblings play an important role in children’s learning and development. Interactions with brothers and sisters provide opportunities to learn about sharing and emotional reciprocity, to develop social skills, to express thoughts and feelings, and to practice resolving conflict. But for children whose brother or sister has a disability, such as a rare chromosome disorder, some of these sibling experiences may be different.”

—**Unique: Rare Chromosome Disorder Support Group** ([www.rarechromo.org](http://www.rarechromo.org))

Having a sibling with a life-limiting illness affects a child differently depending on a multitude of factors: the medical needs of the brother or sister, the parents’ ability to cope, etc. However, what is prevalent is the stunted attention siblings of children with a life-limiting illness often face.

“The kids only share a certain amount of things with their parents because, of course, they want you to know it affects them. But they’re not going to be open to come and say to Mom and Dad, ‘I’m jealous that you’re spending all this time with my sister.’

Yes, it affects them a lot. They miss their sister, but they miss their parents too.”

—**Floribeth Roman, Parent, National Tay-Sachs & Allied Diseases Association, Inc.**

It is not unusual for siblings to experience feelings of guilt, grief, confusion or anger—and it may be difficult for them to comprehend let alone articulate these feelings to others. But it is important to allow them to express their feelings no matter how vague. By doing this, you are acknowledging them, showing them you care. It may also be helpful for the sibling of the child with a life-limiting illness to confine in a child therapist who specializes in grief counseling and who could be a good ear and aid. Often, a child may be able to tell things to a therapist that they might be reluctant to share with their parents. Also, a child’s understanding of his/her sibling’s illness and prognosis will change as the child develops, and a therapist can help both the child and the parents navigate through these transitions.

If you feel overwhelmed with caring for your loved one with a life-limiting illness as well as the rest of your family, help is out there! One parent shares her experience caring for her two sons, Ryan and Jake (the latter has a rare, life-limiting disease):

“For five years, we hired au pairs to live with our family and provide childcare, normalcy and consistency for Jake’s older brother (and by default our entire family), while we took care of Jake’s needs. It was important to us that Ryan had as normal a home life as possible, and to accomplish that we needed a third set of hands.”

—**Barbara Swoyer, Parent**

If you have other children that are unaffected by a life-limiting illness, there are other resources that you may find helpful. **The Sibling Support Project** ([www.siblingsupport.org](http://www.siblingsupport.org)) believes disabilities, illness and mental health issues affect the lives of all family members. With that in mind, this nonprofit organization aims to support the brothers and sisters of people with special needs.

## SECTION 1: PRESERVING THE FAMILY

Another great resource, **Sibs** ([www.sibs.org.uk](http://www.sibs.org.uk)) is a United Kingdom charity that represents the needs of disabled people. Siblings of those with life-limiting illnesses have a lifelong thirst for information, often experiencing social and emotional isolation while coping with difficult situations.

**Siblings Australia, Inc.** ([www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)) is also committed to improving the support available for siblings of children and adults with chronic conditions, including disability, chronic illness and mental health issues.

In addition, there may be counseling programs provided by your state. Many states have such programs for children under these sorts of situations.

“In our state (Rhode Island) there is a counseling program for siblings of chronically ill children. I see a tremendous amount of merit in it. The director is herself the adult sibling of a chronically ill child and will understand the anger, fear and sadness that are sometimes misinterpreted as behavioral issues in our healthy children.

Here is a link to the program in Rhode Island (<http://www.bradleyhasbroresearch.org/pediatric-behavioral-health/siblink/>), but I don't want to mislead people though as there is a significant waiting list to get accepted.”

—**Shannon Reedy, Director, Chase the Cure**

### Maintaining the Marriage

Caring for a sick and dying child really requires two parents that can work well together, and it is not unusual for the challenges associated with this incredible job to put pressure on a marriage.

“Caring for a medically fragile child can definitely put a strain on a marriage, and probably the biggest thing that I can say for how we coped for it was open communication, being able to make sure that we were on the same page, talking with each other and really coming back to reevaluate and knowing that for each one of us, it's okay for us to change our minds at any point. But we did have to talk about it.”

—**Michelle Cooper, Parent, National Tay-Sachs & Allied Diseases Association, Inc.**

The most effective way to keep a marriage intact is through communication. It is vital to make sure you are each in support of decisions and always aware of what's going on.

“Once you establish communication and once you establish to not hold things in, then you become a team. And that's when things get better.”

—**Floribeth Roman, Parent, National Tay-Sachs & Allied Diseases Association, Inc.**

Adding couples therapy may help you and your spouse establish this vital communication. It can help you both cope with the situation, process your different opinions on approaching your child's illness, and understand each other's fears and concerns. Couples therapy, also referred to as Grief Counseling, can truly make a difference in maintaining your marriage.

## SECTION 1: PRESERVING THE FAMILY

### Involving Extended Friends and Family

The diagnosis of a life-limiting illness can be overwhelming, not only for you, but also for your friends and relatives. They can be unsure of what to say, and they may feel uncomfortable because they may not know what will upset you.

So it is not unusual for relatives and friends to simply disappear to avoid this awkwardness. Afraid of saying the wrong thing, they'll just not say anything at all. If you sense this happening, don't feel afraid to speak up!

You may want to bring in others and tell them about the particulars of the diagnosis: what treatments are needed, the prognosis. People will want to help, but they won't know how. Your loved ones will likely want to support you and your family. Allow them to! Try to be as specific as possible about your wants and needs. Help them help you.

"I think the best approach is to kind of educate them because they don't know anything about our world. I mean, I can't blame them: they have no clue, so the best approach would be to tell families and friends what you want.

If you want their support, tell them, 'I need your support. I need it this way' or 'No, what you said is a little bit hurtful. Let me tell you a little bit about the disease or what we're going through.' I think the biggest thing is communication and telling friends and family what you expect."

—Janelle Marquez, Parent, National Tay-Sachs & Allied Diseases Association, Inc.

But don't feel obligated to keep your extended friends and family always in the loop, if you feel overwhelmed as it is. Relatives should be there to support your family and your decisions. If their roles need to change, don't hesitate to voice your concerns.

"Make decisions by yourself; you don't need to involve everyone in your extended circle in decisions they don't have to live with. Too many cooks in the petri dish are going to make you homicidal."

—Shannon Reedy, Director,  
Chase the Cure

## SECTION 2: SPECIAL EQUIPMENT



Not every child will need or use all the equipment listed below and some of the equipment may not fit into a family's care plan. These are options available to parents to help manage the symptoms and promote comfort.

### Respiratory Equipment

- **Suction Machine:** A suction machine is commonly used to remove secretions (such as saliva) and mucous (gunk) from the mouth, throat, nose and upper lobes of the lungs. Available in both portable (battery operated) and non-portable. Many families prefer the portable battery operated suction machines to allow for more outings with their child. Battery operated equipment are useful in case of power outage. Supplemental suction machine supplies include catheters, i.e., Yankour, flexible (sterile and non-sterile), nasal aspirators.
  - **Nebulizer:** A nebulizer changes liquid medicine into fine droplets (in aerosol or mist form) that are inhaled through a mouthpiece or mask. The nebulizer 'breathing treatments' are commonly used to delivery airway-opening medications such as albuterol (Ventolin®, Proventil® or Airtel®), levalbuterol (Xopenex®) or ipratropium bromide (Atrovent®).
  - **Vest:** The Vest® System is an easy-to-use airway clearance device. Unlike manual chest percussion therapy (CPT), The Vest® System treatment does not require special positioning and breathing techniques. It can be challenging to get insurance coverage for the Vest and it is very expensive. A prescription from a pulmonologist stating it is medically necessary is a good first step.
- The Air Pulse Generator rapidly fills and deflates an inflatable garment, gently compressing and releasing the chest wall up to 25 times per second. This process, called High-Frequency Chest Wall Oscillation (HFCWO), creates mini-coughs that dislodge mucus from the bronchial walls, increase mobilization, and move it along toward central airways. The action also works to thin thick secretions, making them easier to clear. Once the mucus has moved from the smaller to larger airways, it can be easily removed by coughing or suctioning. (source: [www.thevest.com](http://www.thevest.com)).
- **Cough Assist:** CoughAssist is a noninvasive therapy that safely and consistently removes secretions in patients with an ineffective ability to cough. It clears secretions by gradually applying a positive pressure to the airway, then rapidly shifting to negative pressure. The rapid shift in pressure produces a high expiratory flow, simulating a natural cough.

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- **Oxygen Concentrator & Portable Tanks:** Oxygen Concentrators are a safe and convenient source of therapeutic oxygen. They are commonly used alternatives to awkward and potentially dangerous tanks. Oxygen concentrators provide a continuous flow of oxygen (or sometimes a pulse of oxygen as the user inhales) to the user without tanks or cylinders that require re-filling. They are electric or battery powered oxygen delivery systems that extract some of the air from the room and separates the oxygen from the other gases.
- **Hospital bed:** Hospital beds are sometimes used in the home to promote the comfort and well-being of your child and for the convenience and safety of you and other caregivers. Common features include adjustable head and feet, adjustable bed height, side rails, washable mattress and easy to move.
- **Specialized Stroller:** Specialized strollers are like regular children's strollers, but provide more support options and larger weight limits. Your child's physical therapist will evaluate your child's current and future needs and order the appropriate specialized stroller. Some families prefer using larger regular strollers or a combination depending on the outing, and then customizing the strollers with pillows for additional support where needed. There are lots of options available.

### Positioning Equipment

- **Tumble Forms:** Tumble Forms provide soft foam positioning support in a variety of options from carrier and feeder seats to wedges and bolster rolls. Feeder seats can be used for feeding as well as resting. Wedges are used to promote trunk control, head raising and arm and hand movement. Discuss your child's current and future positioning needs with a physical, speech or occupational therapist.
- **Stander:** A stander is an adjustable standing aid that promotes correct alignment of the trunk and lower extremities. Prolonged immobility can cause skin breakdown, discomfort and tight joints and muscles.
- **Bath Chair:** A bath chair is used in the bathtub or shower to make bathing safe and comfortable for you and your child. Your child's physical therapist will evaluate your child's current and future needs and order the appropriate bath chair.

Some families use a Hoyer Lift to assist getting larger children safely in and out of the bathtub. Discuss this option with your physical therapist.

A stander can alleviate these issues but are not right for all children. Discuss if a stander is right for your child with your physical therapist.



## SECTION 2: SPECIAL EQUIPMENT

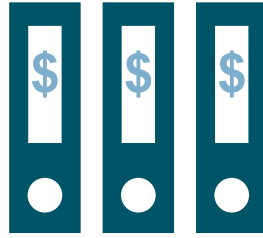
### Types of Feeding Tubes

- **NG (Naso Gastric):** Inserted into the nose and going down to the stomach.
- **G (Gastric):** G-tube is surgically placed directly into the stomach and is used for long-term enteral nutrition. Some hospitals will place a PEG or Bard G tube initially to form the stoma (2-3 months) and then transition to a button g-tube.
- **NJ (Naso Jejunal):** Inserted into nose and going down to the small intestine.
- **GJ (Gastric Jejunal):** Button is surgically placed in the stomach and tubing runs to the small intestine. Can be an alternative to Nissen Fundoplication for children who aspirate.
- **Nissen Fundoplication** is a surgical procedure that wraps the stomach around itself to prevent acid reflux and reduce risk of aspiration.

### Other

- **Pulse Oximeter:** A pulse oximeter is a convenient and noninvasive way to monitor your child's oxygen levels. It simply sits on your child's finger or toe and displays oxygen levels on a monitor. Many also display heart rate. There are three types of pulse oximeter: non-portable that plug into the wall like the ones used in the hospital, hand-held and finger-tip both of which are portable and battery-operated.
- **Apnea Monitor:** An apnea monitor is a device that measures how well your child breathes while sleeping. It checks for apnea, a pause in breathing for 5 to 20 seconds while you sleep. The device also measures air flow, chest movements, heart rate, and oxygen in your blood.
- **Feeding Pump (if using g-tube):** A feeding pump is a small machine, calibrated for accuracy, designed to deliver formula and/or other liquid at a set rate. Generally used when children do not tolerate bolus (all at once through a syringe) feeds.

## SECTION 3: UNDERSTANDING FINANCES



“Most states have some mechanism for supporting families with nursing care when a child gets particularly sick, and we could not have done it without the nurses—and that meant both when she was sick but not in critical condition then also when we transitioned into the end-of-life care. And in both of those settings, having access to medical professionals in the house was critical. And that’s there; you just have to advocate for it.”

—Charlie Lord, Parent, National Tay-Sachs & Allied Diseases Association Inc.

Successfully acquiring financial assistance during difficult times like these is a major concern for families caring for a loved one with a life-limiting illness. The cost of special equipment, doctor appointments, and even just the odds and ends of daily life can begin to add up. You are not alone, and although you may feel the walls of financial stress closing in on you, there are many assistance programs out there that can help!

### Government Assistance Programs (i.e. Medicaid & Medicare)

**Medicaid** (<http://medicaid.gov/>) is a government program that covers the cost of medical care. To qualify for this assistance, your family’s income and assets must be below a certain level, which varies from state to state. And having insurance income doesn’t automatically dismiss you from possibly receiving Medicaid.

Please note that certain qualifications may change in 2014 because of the Affordable Health Act. The **Affordable Health Act**, often referred to as Obamacare, doesn’t allow insurance companies to deny coverage to children with pre-existing conditions (i.e. diabetes, cancer).

Physical limitations may qualify individuals for Medicaid and Social Security income. Contact your state’s **Department of Human Services** for assistance with applying for these financial services.

**Medicare** ([www.medicare.gov](http://www.medicare.gov)) is a federal government program funded through Social Security. Learn more on Medicare and Social Security through the **Social Security Administration** ([www.ssa.gov](http://www.ssa.gov)) and click “Disability.” The Medicare government website ([www.medicare.gov](http://www.medicare.gov)) also answers questions, provides information and referrals to state Medicare offices.

If you are unsure of your rights and benefits with Medicare, the **Medicare Rights Center** ([www.medicarerights.org](http://www.medicarerights.org)) helps guide you through the system to get you quality care. It will also help you apply for programs that will reduce your costs for prescription drugs and guide you through the appeals process if a Medicare drug plan denies your coverage for a certain prescription.

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One parent advocate shares her experience with Medicaid and the Katie Beckett Waivers, which she has found helpful while caring for a child with a life-limiting illness:

“We’ve applied for Katie Beckett Waivers in two states that additionally cover some copays via non-income driven Medicaid. I’ve been very surprised to learn other parents are unaware they can access this as well. Some conditions automatically qualify a family for additional coverage through Medicaid, even if they have a commercial health plan and regardless of their income.”

—**Shannon Reedy, Director, Chase the Cure**

In addition to Medicare, there are other government assistance programs, such as **The Bureau for Children with Medical Handicaps** that support those with rare, life-limiting illnesses.

If you have questions regarding how to apply for Medicare, Medicaid, disability and survivor benefits, please access the **Centers for Medicare & Medicaid Services** ([www.cms.gov](http://www.cms.gov)). A social worker assigned to your case can also be a wealth of information and help with navigating the system to access aid.

### Supplemental Security Income

**Supplemental Security Income (SSI)** can help supplement income for an eligible disabled person or family member. The family/person must have a low income and limited assets. Paid monthly, this supplemental payment amount varies from year to year and from state to state. In order for your child to receive SSI, you must apply on your child’s behalf.

In most states, Medicaid is given to any adult or child who gets Supplemental Security Income, but you may need to apply separately.

### The Appeals Process

“There is one other thing I would tell a family too is that insurance companies will deny you over and over. You have to keep pushing because if they say no to you, it doesn’t mean, ‘we’re not going to do it.’ It means, ‘No, we’re not going to do it today—you have to apply three or four times to get your approval for what you need.’

So you have to fight with insurance companies until they give you what you need because most insurance companies have you covered, they just don’t want to do it because it costs a lot of money.”

—**Rod Marquardt, Parent, National Tay-Sachs & Allied Diseases Association, Inc.**

It is not unusual for some claims to be denied or for some insurers to not cover a test, procedure, service or treatment. But before appealing, here are some things you should do first:

- Ask your customer service representative why the claim was denied.
- Review your health insurance plan’s specified benefits.
- If the plan is through an employer, contact the health plan administrator to learn why it was refused.
- Ask the doctor to explain why s/he requested this service or test to be done (and keep this letter for your appeal).

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Once you have done these steps, you may re-submit your claim with the denial letter, your doctor's explanation in support and any other information that supports your claim. Sometimes, the claim was simply "miscoded." However, if this isn't the case, there are other steps you may want to complete:

- Postpone payment until the issue is resolved.
- Resubmit the claim, requesting a review.
- Speak with a supervisor who can veto the decision.
- Request a written response.
- Maintain a record of dates, names and other pertinent information regarding the denial.
- Appeal in writing and explain its necessity to be included in the plan.
- Explore getting the claim reviewed externally\*\*
- Consider legal action

\*\*An external review is completed by people outside your health plan. Learn more through [www.healthcare.gov/news/factsheets/2012/06/appeals06152012a.html](http://www.healthcare.gov/news/factsheets/2012/06/appeals06152012a.html).

Also learn about the appeals process in more detail through the **Kaiser Family Foundation's** "A Consumer's Guide to Handling Disputes with Your Employer or Private Health Plan" (<http://kff.org/health-costs/report/a-consumer-guide-to-handling-disputes-with-your-employer-or-private-health-plan/>) and the **Patient Advocate Foundation's** "Your Guide to the Appeals Process" ([www.patientadvocate.org/pdg/pubs/appeal\\_guide.pdf](http://www.patientadvocate.org/pdg/pubs/appeal_guide.pdf)).

The **Patient Advocate Foundation** ([www.patientadvocate.org](http://www.patientadvocate.org)) in general is a great resource too, working with patient and insurer, employer and/or creditors to resolve insurance,

job retention and/or debt problems related to the diagnosis (with the help from case managers, doctors and attorneys). This resource can help you during times when your claim is denied.

Please review this sample complaint letter to a State Insurance Commission, if you need guidance putting together an argument: <http://www.rarediseases.org/docs/SampleComplaintLettertoStateInsuranceCommission.pdf>.

### No insurance?

Health insurance coverage reduces the often weighty medical costs associated with diagnosing a treating a child's illness. Therefore, it is important to have accurate, up-to-date information and a good understanding of your financial situation and insurance coverage. But there are options available for you and your family if health insurance is not within reach through your employment.

"When we were educated about the resources—like for example in California, there's a medical program, which is a special insurance for kids with special needs—I was able to work part-time and also at the same time I have income to help. You have to know what the resources out there are before you make a big decision to quit your job."

—**Janelle Marquez, Parent, National Tay-Sachs & Allied Diseases Association, Inc.**

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The most valuable asset your job could provide is health coverage, but many do not have that at their disposal. In these instances, there are still programs and assistance available. For instance, **Children’s Health Insurance Program** (<http://www.medicaid.gov/Medic-aid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/Childrens-Health-Insurance-Program-CHIP.html>) offers low cost health insurance to uninsured children and pregnant women in families with incomes too high to qualify for state Medicaid programs but too low to pay for private coverage.

Each state varies with their guidelines and cost. The Program covers doctor visits, medicines, hospitalizations, dental care, eye care, medical equipment, etc. However, those that enroll in Medicaid usually are not eligible for state-sponsored health insurance programs.

If you have no insurance coverage, the **Partnership for Prescription Assistance** (<http://www.pparx.org/>) is another option that helps with prescriptions. One parent advocate shares a resource she has found exceedingly helpful, MassHealth (<http://www.mass.gov/eohhs/gov/departments/masshealth/>).

“We were told about MassHealth not by—surprising to me still— my pediatrician (or any of Jake’s doctors for that matter), but by another parent. We applied and were accepted to MassHealth, which provided secondary, state-based insurance for Jake. What had equaled approximately \$1,000 per month in increased medical expenses when Jake initially became sick was now almost entirely taken off our plate.

Currently Jake has been accepted into the highest level of coverage that we are aware of, and at no cost to our family. Re-evaluation of coverage and premiums occurs every year. MassHealth covers most durable medical equipment, medical co-pays, diapers and other supplies, most medications, and nursing and PCA coverage as well as other items.”

—**Barbara Swoyer, Parent (Note that MassHealth is a program particular to Massachusetts)**

### Additional Resources

Many states also have **Temporary Assistance for Needy Families**, a grant program that gives monthly cash payments that help pay for food, clothing, housing, utilities, transportation, phone and medical supplies. Access each state’s health department, including Temporary Assistance for Needy Families through <http://www.hhs.gov/recovery/programs/tanf/index.html>.

This program can help cover additional expenses that many do not consider immediately after a diagnosis: transportation, lodging (during treatment, away from home), special food, childcare for other children not part of your health plan, special equipment, etc.

Another great resource to check is The **Henry J Kaiser Family Foundation’s** “State Health Facts” (<http://kff.org/statedata>), which provides free, up-to-date health data for each state.

## SECTION 4: FINDING SUPPORT



Having government and insurance support is a strong weapon against the frailty one can often feel when caring for their loved one. Additional support can come from many sources—family, friends, even other advocates. Between managing the attention of siblings, learning how to use a new medical device and talking with your insurance policy representative, building a foundation of support is an important part of your journey.

### Other Parent Advocates

“Unfortunately the experts are the parents of these children, and I received more help from them than I was able to receive from the doctors. And it’s a sad thing that we are the ones educating the professionals versus the other way around.”

—Floribeth Roman, Parent, National Tay-Sachs & Allied Diseases Association, Inc.

Parenting a child with a life-limiting disease can be isolating. The reality is that your parenting choices will be largely different than those of other non-affected parents. This is why joining a rare disease support group can be very helpful—in more ways than one.

Knowing that you are not alone in your struggle can be both stress-relieving and eye-opening. Hearing the experiences of other parents and patients can help you resolve these feelings of confusion and help you answer questions you may not have even known you had.

“The only advice I can offer to a parent of a child with a rare disease is to keep well organized and detailed records because the parents invariably end up being the experts, and they often have to repeat the same information as succinctly as possible to many different professionals. The absolute best therapy for us was meeting other children and families with metabolic disorders. There is nothing that can compare to that kind of real support, even if it is on social networking sites.”

—Julia Boonnak, Parent, CDG Family Network

If you are unable to travel or are short on time/money, support groups are still at your disposal! The internet has created ways for people from all over the world to connect.

Invaluable resources for many, support groups help identify ways to approach situations and challenges. Members can offer recommendations on specialists, advice to prevent complications and, most importantly, a listening ear! If you don’t fully understand your child’s diagnosis, support group members often can shed light in that area as well.

“Other families are, and were for us, a huge resource in everything from different ways to think about the care of a child to how to advocate for resources to just the assurance that you can make it.”

—Charlie Lord, Parent, National Tay-Sachs & Allied Diseases Association, Inc.

If you are interested in finding and joining a support group, the NCATS Office of Rare Diseases Research has compiled a list of advocacy organizations that support rare diseases ([http://rarediseases.info.nih.gov/files/Patient\\_Support\\_Groups\\_ORDR%20List.pdf](http://rarediseases.info.nih.gov/files/Patient_Support_Groups_ORDR%20List.pdf)).



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### Palliative/Hospice Care

**Pediatric palliative care** is specialized care for children with serious illnesses as well as their family. It focuses on providing relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. It includes the physical, emotional, social and spiritual elements of care. The goal is to improve quality of life for the child and also the family.

Pediatric palliative care is provided by a team of doctors, nurses and other specialists who work together with a child's other doctors as an extra layer of support.

Pediatric palliative care is appropriate at any age and at any stage of an illness and can be provided along with treatments meant to cure. If you have questions on pediatric palliative care, please read more information in the **Appendix**.

**Hospice care** is an extension of pediatric palliative care and often palliative care is delivered through hospice providers who are trained in helping families realize their quality of life goals for their child. For the most part, hospice and palliative care are interchangeable words and you can ask your doctor or team about getting palliative or hospice support for your child.

Ideally, **palliative care begins at the time of diagnosis**, so that families have this extra layer of support all the way along their child's continuum of care. Grief begins at the time of diagnosis, when the family learns that the child is sick and that the future is not as they expected. When this grief and shift in expectations is addressed, it can be managed and the family can begin coping with 'the new normal.'

There is a misconception that palliative care and hospice care is only reserved for end-of-

life care, and many do not start it as soon as they should. Why? Sometimes the patient, a family member or the doctor believes it is the equivalent of "giving up" and all hope is lost. But this is a misconception; these types of care have proved incredibly helpful for many patients.

In most cases, an interdisciplinary healthcare team manages the hospice care: doctors, nurses, counselors, social workers, home health aides, clergy, therapists and trained volunteers.

"Hospice too, from the start, developed a team of people to work with us. So there was the nurse that came in weekly. There were also the social workers who came in regularly. There was a chaplain that came while I was at work (so I never saw her) once a month and our volunteer.

Once hospice was able to get us set up, a pediatrician was able to come in the home. We no longer needed to go to the hospital. The problem with going to the hospital was he got exposed to germs that otherwise he wouldn't. And also the pediatricians and the doctors in the hospital have never seen this disease. They don't know what's going on."

—Rod Marquardt, Parent, National Tay-Sachs & Allied Diseases Association, Inc.

Usually costing less than hospitals, nursing homes and other institutional settings, palliative/hospice care can be provided for through Medicare, Medicaid in most states, the Department of Veterans Affairs, most private insurance plans, HMOs and other managed care organizations. Also, several hospices offer free services to patients who can't afford payment.

To learn more about and find a pediatric palliative/hospice program within your area, explore

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the **National Hospice & Palliative Care Organization's** website ([www.nhpco.org](http://www.nhpco.org)) and the **Hospice Foundation of America's** website ([www.hospicedirectory.org](http://www.hospicedirectory.org)).

### Grief Counselors

Grief is a natural and healthy byproduct of receiving a life-limiting diagnosis for a loved one. “Anticipatory grief” is the name for what parents experience as their expectations for their child’s life change with the diagnosis and they adapt to their ‘new normal.’ It means grappling with and grieving a loss before it completely unfolds. Most of the support that people receive in anticipation of and after a loss comes from friends and family. Doctors and nurses may also be great sources of support. Professional grief counseling/therapy is also helpful and can play an important role in a family’s ability to cope.

**Grief counseling** helps people cope with grief, mourning and loss. Grief counseling can be provided by professionally trained people or in support groups where grieving people help other grieving people. All of these services may be available in individual or group settings. Here, two parents of a young child with a life-limiting illness share their experience with a grief counselor:

“We went out and found a grief counselor from children’s hospital that we began to meet with on what started as a monthly basis. And then once she got sicker, it became bi-weekly, and by the end, it was weekly. We would have moved her into the house if we could have.”

—Charlie and Blyth Lord, Parents,  
National Tay-Sachs & Allied Diseases  
Association, Inc.

Grief counseling aims to:

- Help the person talk about their loss.
- Help the person identify and express feelings related to the loss (such as anger, anxiety, guilt, helplessness or sadness).
- Provide continuous support.
- Identify coping problems the person may be experiencing.

One parent, although she had to discontinue her work with a grief counselor, experienced many of these aims:

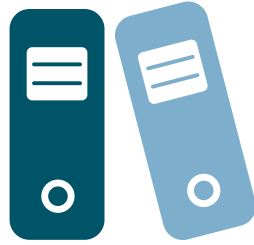
“I personally sought out a grief counselor to help me cope with our family situation and the ‘anticipatory grief and loss’ that I was experiencing. She was helpful to me, but logistics and expenses contributed to my stopping that therapy after about a year or less. I do, however, feel that therapy will be useful to us as Jake moves from declining health to end-of-life stage, and probably after.”

—Barbara Swoyer, Parent

**Bereavement Support** refers to grief therapy after the loved one dies, either as a one-on-one or in a support group. The goal of bereavement therapy is to help the surviving family members cope with the natural grief in the wake of their loss. While there is no right or wrong way to grieve, there are healthy ways to cope with the pain that, in time, can renew you and permit you to move on.



# APPENDIX



## Pediatric Palliative Care: [GetPalliativecare.org](https://www.getpalliativecare.org/)/the Center to Advance Palliative Care

### What Is Pediatric Palliative Care?

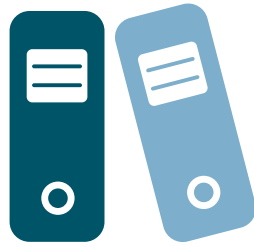
When a child is sick, everyone in the family is affected. Pediatric palliative care is specialized care for children with serious illnesses— including genetic disorders, cancer, prematurity, neurologic disorders, heart and lung conditions and others—as well as their family. It focuses on providing relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. It includes the physical, emotional, social and spiritual elements of care. The goal is to improve quality of life for **the child and also the family**.

Pediatric palliative care does several things:

- (1) It relieves the child's disease symptoms, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.
- (2) It helps with communication and coordination of care between the medical team and the parents. When caring for pediatric patients, doctors and parents are often faced with difficult decisions around the benefits versus burdens of medical technology and the impacts on the child's quality of life. With the close communication that palliative care provides, families are better able to make choices that are in line with their values, traditions and culture. This improves the well-being of the entire family and promotes emotional and spiritual healing even as the disease persists.

In short, pediatric palliative care helps the child and the family to have the physical, emotional, and mental strength to carry on with daily life and provide the best quality-of-life for the affected child and the family.

# APPENDIX



## Benefits of Pediatric Palliative Care

Palliative care for children improves quality of life for children suffering from serious illness and the family. Pediatric palliative care specialists focus on your whole child and how your child's illness and treatment affect the entire family.

The palliative care team supports your child and family every step of the way. Working together with your primary doctor, the palliative care team provides an extra layer of support through:

- Close communication and time spent with the patient and family
- Identification of care goals and values
- Guidance with difficult and complex treatment choices
- Expert management of pain and other symptoms
- Help navigating the healthcare system
- Emotional and spiritual support for you and your child

It is important to remember that palliative care is an extra layer of care on top of curative care. By blending palliative care with curative treatments, you provide your child and family with the most complete medical care possible. Therefore, it is best to start palliative care as early as possible.

# RESOURCE GUIDE



## Appealing an Insurance Claim Denial

**Kaiser Family Foundation’s “A Consumer’s Guide to Handling Disputes with Your Employer or Private Health Plan”** (<http://kff.org/health-costs/report/a-consumer-guide-to-handling-disputes-with-your-employer-or-private-health-plan/>): The Kaiser Family Foundation walks you through the appeals process in this report, helping you navigate your plan’s internal appeals procedure and your state’s external review process for disputes with your employer or private health plan. Unfortunately, this guide can’t be used for resolving disputes with your Medicare or Medicaid Health Plan because these have their own procedures for resolving disputes.

**Patient Advocate Foundation** ([www.patientadvocate.org](http://www.patientadvocate.org)): This organization works with patient and insurer, employer and/or creditors to resolve insurance, job retention and/or debt problems related to the diagnosis (with the help from case managers, doctors and attorneys). This resource can help you during times when your claim has been denied.

**Patient Advocate Foundation’s “Your Guide to the Appeals Process”** (<http://www.patientadvocate.org/requests/publications/Guide-Appeals-Process.pdf>): This guide, courtesy of the Patient Advocate Foundation, was inspired by patients and family members who work diligently at fighting a disease and the right to treatment. This guide was designed to help navigate the appeals process, giving suggestions and advice.

## Caring for Healthy Siblings

**Sibs** ([www.sibs.org.uk](http://www.sibs.org.uk)): A United Kingdom charity, Sibs represents the needs of disabled people. Siblings of those with life-limiting illnesses have a lifelong thirst for information, often experiencing social and emotional isolation while coping with difficult situations.

**Siblings Australia, Inc.** ([www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)): This organization is committed to improving the support available for siblings of children and adults with chronic conditions, including disability, chronic illness and mental health issues.

**The Sibling Support Project** ([www.siblingsupport.org](http://www.siblingsupport.org)): This organization believes disabilities, illness and mental health issues affect the lives of all family members. Therefore, this nonprofit organization aims to support the brothers and sisters of people with special needs.

## Finding a Support Group

**The NCATS Office of Rare Diseases Research** ([http://rarediseases.info.nih.gov/files/Patient\\_Support\\_Groups\\_ORDR%20List.pdf](http://rarediseases.info.nih.gov/files/Patient_Support_Groups_ORDR%20List.pdf)): This link goes directly to a list of advocacy organizations which support the rare disease community. If your loved one has just been diagnosed with a rare, life-limiting disease, connecting with others through a support group or advocacy organization can be immeasurably helpful.

# RESOURCE GUIDE



## If You Lack Insurance

**Children’s Health Insurance Program (<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/Childrens-Health-Insurance-Program-CHIP.html>):** This program provides health coverage to nearly 8 million children in families with incomes too high to qualify for Medicaid, but can’t afford private coverage. Like Medicaid, Children’s Health Insurance Program is administered by the states

**Partnership for Prescription Assistance (<http://www.pparx.org>):** The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free. If you do not have insurance coverage but are in need of certain prescription medications, this is a resource you may find helpful.

## Locating Hospice & Palliative Care Programs

**GetPalliative.org/The Center to Advance Palliative Care ([www.GetPalliativeCare.org](http://www.GetPalliativeCare.org)):** Is an incredible resource that provides detailed information, resources, and a provider directory. It also provides an interactive questionnaire to assist you in determining whether palliative care might be appropriate for you or a loved one. The Center to Advance Palliative Care provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care teams in hospitals and other health care settings.

**Hospice Foundation of America ([www.hospicedirectory.org](http://www.hospicedirectory.org)):** Locate a hospice through this Hospice Directory. Also learn more about this type of care through its Frequently Asked Questions or emailing them a question directly.

**National Hospice & Palliative Care Organization ([www.nhpco.org](http://www.nhpco.org)):** The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. If you are searching for a program within your area, this resource provides regional lists.

# RESOURCE GUIDE



## Medicare & Medicaid

**Center for Medicare & Medicaid Services ([www.cms.gov](http://www.cms.gov)):** The Center for Medicare & Medicaid Services administers Medicare and works in partnership with state governments to administer Medicaid, the state Children’s Health Insurance Program and health insurance portability standards. It also answers questions about applying for Medicare, Medicaid, disability and survivor benefits.

**Medicaid (<http://medicaid.gov>):** This health program assists families and individuals with low income and resources. This government website answers questions and provides information.

**Medicare ([www.medicare.gov](http://www.medicare.gov)):** This federal government program is funded through Social Security. This direct link to the Medicare government website answers questions, provides information and gives referrals to state Medicare offices.



**Medicare Rights Center ([www.medicarerights.org](http://www.medicarerights.org)):** The Medicare Rights Center is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives. It helps guide you through the Medicare system to get you quality care.

**Social Security Administration ([www.ssa.gov](http://www.ssa.gov)):** The Social Security Administration website provides a lot of invaluable information. You can find more information on Medicare and Disability coverage.

## Other Helpful Financial Resources

**Henry J. Kaiser Family Foundation’s “State Health Facts” (<http://kff.org/statedata>):** Kaiser is a nonprofit, private operating foundation focusing on the major health care issues facing the United States, as well as America’s role in global health policy. Access this direct link to read free, up-to-date health data for each state.

**Temporary Assistance for Needy Families (<http://www.hhs.gov/recovery/programs/tanf/index.html>):** This is a grant program that gives monthly cash payments to help with food, clothing, housing, utilities, transportation, phone and medical supplies. Access the state health department through this direct link.



# LET OTHERS BENEFIT FROM YOUR KNOWLEDGE BY SHARING YOUR TIPS AND TRICKS!

If you would like to contribute your experience or have a comment/suggestion, please enter it on the toolkit's online form.



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