

Understanding the Lived Family Experience



Learning Objectives

After reviewing this Guide you will be able to:

- Identify the central themes in the lived experience of caring for a child with serious illness
- Formulate strategies to support families as they accompany their child

Diagnosis, Prognosis and Anticipatory Grief

Communicating with the Family

Learning of a child's rare or serious illness diagnosis upends a family's world. It can mean many things: the end of an exhaustive diagnostic odyssey; an explanation that helps address guilt about causation (or creates guilt about causation); connection with a community of other families facing similar challenges—and a sense of isolation and distance from pre-illness life; a new understanding of what is likely to lie ahead. And as one CPN parent has said, for most families "any new diagnosis is a loss."

We understand this to mean the loss of some degree of hope of a normal life for one's child. Nevertheless, parents want to know that hope is always a part of the care plan—even though the focus of that hope may shift. The language and behavior of clinicians play a vital role in communicating to the family that the care team sees and values a whole child, not just a diagnosis or impairment.

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There is also a delicate balance to be maintained between using unfamiliar terminology that might overwhelm caregivers, and being overly simplistic which insults the family. In fact, many parents become well versed in medical terminology, and may find it easier to connect to and trust a team that speaks “their” language. As the connection forms and deepens, families will likely become more comfortable in sharing their worries and fears, spoken and unspoken:

- That the child will suffer
- That the marriage or partnership will disintegrate
- That the family will fall apart; or even
- That the caregiver will not survive the illness

Anticipatory Grief

Beginning at diagnosis, parents will experience a range of emotions, possibly fear, anger and/or sadness. It can be helpful to reassure them that these feelings are normal and part of grief; to give those feelings a name. Anticipatory grief means grappling with and grieving the losses now of what was expected or some of the hopes and dreams for your child long before the future, whatever that will be, unfolds. This grief can take up a lot of room in parents' minds and hearts.

Key Hardships and Ongoing Worries

This new reality brings with it other, practical challenges. A serious illness takes families out of their regular routine and requires new or enhanced kinds of support. Depending on a family's circumstances, location and available resources, finding and securing these resources is a huge stressor.

A new culture: Entering the hospital system whether for diagnosis or treatment and symptoms management—and being thrown into a medical world and culture is overwhelming, confusing and terrifying for most. Parents want to protect their child from the unknown; from harm and medical trauma. Families must learn the hierarchy of medical staff, terminology, schedules and protocols used within the hospital. Another stressor for families is moving from one department, a clinic to a hospital room or an intensive care bed, to another specialized unit compounds the stress, as children and families must begin again with different staff and location, etc.

Discharge to home, while longed for, is fraught with new worries: learning new equipment, establishing new routines, and engaging with new caregivers for the child. Helping to set clear expectations and timelines around discharge will help the family adjust.

Financial hardship: The cost of ongoing care for a medically complex child is significant. There are medical equipment, supplies and procedures, as well as transportation, child care for siblings, and meals on the go that insurance does not cover. Families may need to move or adapt their home, and purchase a new vehicle to accommodate their child's needs. Often one parent needs to be present for long hospital stays and frequent medical appointments, which may require giving up a job and the loss of that income.

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Scheduling: Frequent hospital admissions, outpatient appointments and at-home therapies consume much of a family's time. Often a child sees multiple subspecialists, all with different clinic hours. Coordinating appointments, therapies, deliveries of home care supplies, and nursing support is the responsibility of the caregiver and can be overwhelming. And that is before unexpected medical complications, which may make committing to a non-urgent medical appointment or even a fun activity for the family (sick child, siblings or parents) subject to change or cancellation. Families with other children may also need to find child care, or be forced to bring siblings to appointments—or sometimes miss an appointment. These issues can be disheartening for parents, and they impact siblings and other family members who also deserve attention to their needs.

Transportation: In addition to the scheduling issues, for many families the logistics of getting to and from appointments may be a challenge. If a family relies on one vehicle or uses public transportation, and/or if the child has medical equipment that requires transport, the situation is further complicated. The cost of gas, parking fees and fares can add hardship.

Caring for siblings: Siblings will have their own response and understanding of what is occurring. They have their own needs that require attention and support. Siblings may seek information, or have questions that they are afraid to ask. They may feel jealous and left out when extra attention is paid to their sick brother or sister. Siblings may be shuttled between family and friends, or may have to give up their own activities to accommodate the demands of their sibling's medical care, leaving them feeling isolated. They may act out at home or school. On the other hand, some siblings take on the role of a secondary caregiver, demonstrating protective impulses and a sense of responsibility over their sick sibling. Some siblings exhibit both sets of behaviors at different times. Parents, meanwhile, often experience feelings of guilt for not being able to provide necessary attention and time to their healthy children.

Marriage; parenting relationship: A child's serious illness may mark the first time that parents will face such extreme stress and complex decision-making. Each may experience different feelings at different times—and the feelings may not always be aligned. Communication styles, learning styles, information needs and coping styles are often different. Each parent may also need to take on new or increased responsibilities at home, work, or in caring for the ill child. The other stressors—financial, logistical, siblings, community—may exacerbate feelings of frustration and anger. Yet the majority of relationships survive; in fact, some are strengthened.

Community: All of these concerns can result in increasing feelings of isolation for members of the family. There is little time to nurture relationships when caring for a child with a serious illness, although many families want to seek out others who will understand their feelings and the practical realities of their life. They may seek out others who have had a similar experience, and members of the medical community as well. Relationships with family and friends may change.

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A Day in the Life of the Family

Asking about a child's typical day at home often provides a new appreciation for the complex caregiving (scheduling, medication management, therapies, interrupted sleep, etc.) that are needed to support a child at home.

See a real-life example, contributed by a CPN parent, of a family's day-in-the-life schedule at the last page of this document.

Palliative Care: What It Is and How It Helps

The family's illness journey largely focuses on curative measures, but a growing number of medical centers also offer pediatric palliative care (PPC)—or practice “palliative-aware” medicine. The term “palliative” refers to a wide range of treatments and interventions that complement disease-directed care, that may be provided by a primary clinician or an interdisciplinary team of physicians, nurses, therapists and psychosocial clinicians.

Many people have misconceptions about palliative care and what it is. Some families will initially be deterred by the term, associating it with hospice and confusing palliative care with end of life, or giving up. In fact, palliative care is appropriate for any stage of serious illness, and can be delivered along with disease-directed, curative treatments. Palliative care emphasizes and encourages parent (and child, if appropriate) involvement in decision-making that reflects the family's goals, values and beliefs. This is to ensure that the care of the child and interventions respect the individuality and uniqueness of the child and family. The goal is that a child lives as well as possible for as long as possible.

Many families regard their PPC providers as a lifeline, and wish that they had known about, or agreed to, this support earlier. For this reason, Courageous Parents Network strongly advocates for inclusion of palliative care services in the care plan.



Conclusion

Families living with a seriously ill child experience a constellation of highly disruptive emotional, psycho-social and practical challenges. Appreciating these will help clinicians, friends, and family members grow in empathy and respect for the strength and courage of parents and other close caregivers. Engaging with parents in family-focused care can create a sense of agency and control over this unimaginable circumstance.

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Resources for Clinicians



CPN Guides

“Introducing Families to Palliative Care”

Materials and suggested scripts to help clinicians introduce the value of palliative care to families.

<https://courageousparentsnetwork.org/guides/introducing-pediatric-palliative-care-to-families>

“Shared Decision-Making”

A guide explaining the family experience of decision-making and ways to help families feel confident and valued as members of the care team.

<https://courageousparentsnetwork.org/guides/shared-decision-making>

Introducing Families to Courageous Parents Network

A guide to assist clinicians in introducing CPN to families so that they might hear other family perspectives and feel less isolated.

<https://courageousparentsnetwork.org/guides/introducing-families-to-cpn>

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Below is a real-life example, contributed by a CPN parent, of a family's day-in-the-life schedule.

Note: Courageous Parents Network does not recommend or endorse any treatments, including interventions, protocols and/or medications. Please consult your medical team.

Name: JJ DOB: June 9, 2006

Medical Problems:

Myoclonic epilepsy 8/5/2008
Developmental delay non verbal and non ambulatory
Regression
Heart murmur 6/2007 Echo 4/2009 showed nothing abnormal
Anemia 5/2008
Aspiration on liquids 7/2010 (nectar thickened)
7/2012 thicken more nectar thickens 3 not 4oz
Tremor (unknown date but before age 1)
Urinary Cathing 12 French as needed (if JJ has not urinated in four hours during awake time)
G-Tube 11/13/12
Mic-Key button - 16 French 3.5 CM 3/15/2013
Rare Genetic disease identified 2013
Mildly prolonged QT intervals 8/2020

Daily Activities/Specialist Appointments:

Epilepsy
Ortho
Psychiatry
Complex care
Urology
Endocrinology
Pulmonology
Cardiology
Aerodigestive
ORL metabolic
Palliative care
PT 3x/week
OT 3x/week
School 4x/week
Speech therapy 2x/week

Allergies:

No known allergies but we need to avoid
Augmentin causes diarrhea
Zonagran
Zarontin causes vomiting
Gabapentin

Food recipe and feeding times:

24oz Compleat Pediatric 7.5 Tbsp. baby cereal
2-4 oz # 2 baby food total & 2 jar baby food meat
Applesauce mix 6 oz applesauce 10 oz water
Feed times each 100 ml bolus plus 60 Applesauce mix
30 ML water to follow by gravity
9a, 10a, 11:15a, 12:30p, 2p, 3:30p, 5p & 6:30p

Medications:

Meds given at 8:30a, 1:30p, 8p and as needed for symptom management, seizure activity

Calcium carb 1.250mg/5ml	2ml at bed
Centrum Vitamin	1/2 tab am
Culturelle Kids	1 packet AM
Glycopyrrolate 1mg per tap	2 tab A.M. 1tab 1:30 & 2 tab Bed
Cyproheptadine 2MG/5ML	10 ML @ Bed
Valproic Acid 250 MG/5 ML	5 ML A.M. & 1:30 P.M. 7.5 ML @ Bed
Diazepam 5MG/5ML	7.5 ML A.M. 6 ML 1:30 & 17.5 ML @ Bed
keppra 100MG/1ML Brand Only	22 ML am and 21ML 1:30 and @ Bed
Lamical 25 mg tabs Brand Only	5 Tabs A.M. 4 tabs 1:30, 3 tabs @Bed
Levocarnitine 100MG/ML	3.3 ML 3 Times a day
MiraLAX 17.5 g	1 cap @ Bed
Motegrity 2MG	1 pill in morning
Nexium 20MG packet	1 packet in morning
Onfi 2.5 MG/1ML Brand Only	5 ML in am & 4.5 ML at 1:30
Vitamin C 500mg chewable	1-3 pills in morning
Zyrtec	10 ML once a day
Nayzilam 5mg per spray	1 spray Per nostril (10mg) for seizure more than 5 mins
Lorazepam 2MG/ML	0.5 ML @ 10, 15, 20, 25 minute seizure mark
Diastat 12.5 mg rectal	Give one dose at the 30 minute mark