Cameron’s Arc: Creating a Full Life
Teaching and Resource Guide

This guide was originally authored by Marcia Levetown, MD and Richard Goldstein, MD in 2007. It has been updated by Jori Bogetz, MD and Richard Goldstein, MD in 2019.

Acknowledgement

A special thanks to Blyth, Charlie, Taylor, Cameron and Eliza Lord for sharing their very private, poignant, and painful, yet inspiring life story in the hope that it will enable better care for all families facing such challenging circumstances. The project staff and consultants feel honored to have worked with all of you. The AAP gratefully acknowledges: Richard Goldstein, MD for being a role model for community pediatricians and pediatric residency directors, for sharing his journey in caring for Cameron and her family, and for his vision in bringing this important project, culminating in a unique teaching tool, to fruition; Meg Comeau for her passion and her perspective as a parent of a special needs child and her wealth of expertise as a healthcare professional; Marcia Levetown, MD for her expertise and leadership in the project and in the development of the teaching guide; Jeff Lobas, MD for sharing his experience as a physician, residency program director and bereaved parent to the project despite personally difficult circumstances; Whit Garberson, MSW, for his enthusiasm, care and thoughtful critique; and, Lauri Levin, MSW, whose organizational skills, clear thinking and dedication saw this project through. And most importantly, thank you to the members of the Lord Foundation for reaching beyond your own families in hopes of helping others- pediatricians and those with whom they work and those whom they serve. For this is the true legacy of Cameron and Hayden Lord. In this gift to others, they achieve eternal life.

Learning Objectives

The purpose of this learning module is to help learners in pediatric settings such as medical students, residents, fellows, faculty, practicing physicians, members of other health care disciplines, and health care consumers to

1. Recognize the role of and skill set needed by the primary care physician and medical home in caring for children with serious illness.
2. Describe the role of effective communication in managing the care of children living with life-threatening conditions and their families.
3. Define and demonstrate patient- and family-centered care in family-professional partnerships.

This learning module addresses the role of a primary care pediatrician and the health care team in supporting families with a seriously ill child. Cameron’s Arc, the associated documentary video, is a project of the American Academy of Pediatrics National Center of Medical Home Initiatives for Children with Special Health Care Needs and the Courageous Parents Network, a parent and professional partnership that seeks to empower parents and families of children living with serious illness.
The Need
While rare in primary care pediatrics, some children in each practice will experience serious health conditions and some will die during childhood. Approximately 500,000 children in the United States are living with a life-altering, serious illness. A “serious illness” is a health condition carrying a high risk of mortality AND either negatively impacts a child’s daily function or quality of life, OR excessively strains the child’s caregivers. The model of care most commonly used in the United States today largely leaves the care of these children and families to specialists. While specialists have a great deal of technical expertise and many well-designed institutional supports to help them do their work, patients and families often turn to their primary care pediatricians for compassionate, community-based support and whole-family perspective in these extraordinary and deeply challenging circumstances. They need and want the help that community-based pediatricians who provide family-focused continuity of care can offer.

Families place great value in their long-term, trusting relationships with their primary care pediatricians—physicians who understand their family, their perspectives, their community, and their resources. This relationship becomes especially important when the unexpected and unwelcome happens. In these circumstances, primary care pediatricians have a critical and complex role to play. Ideally, the pediatrician will continue to act as the primary provider for the child and family, advocating for the child by offering a coordinated medical home in partnership with the family and by sifting through the jumble of information that can often confuse families. Through smart and sensitive medicine, effective symptom control and empathetic communication, pediatricians can provide the kind of trusted care that sustains the family and child, assisting them in making the best decision for their individual needs, and in so doing prevent unnecessary additional suffering that too often accompanies these tragic situations. They can help families move beyond the seeming injustice of their predicament by helping them create a good quality of life for their child and family while gathering gentle, lasting memories. With such support, regrets can be reduced and loving parenting for all children in the family can be maintained.

The Film
*Cameron’s Arc* will introduce you to a family who had the support and care of their child’s primary physician from the beginning of the difficult journey, supplemented by specialists when needed. The story of this pediatrician and this family speaks to a basic element of doctoring—compassion and the ideals that lead people to take on the care of vulnerable lives for a career. The narrative is meant to stimulate reflection and discussion of the intense moments that go into successfully caring for a child and family, even, and perhaps especially, when the expected outcome is death.

Cameron Lord was diagnosed with Tay-Sachs disease at the age of 6 months. She had none of the standard risk factors that might have led to prenatal testing, making her diagnosis a shock to her family and doctor. She died at 2 years of age. The film is constructed from of a series of interviews with Cameron’s parents, Blyth and Charlie Lord, and her pediatrician, Dr. Richard “Rick” Goldstein, a primary care pediatrician practicing in Cambridge, MA at the time. Charles Berde, MD, PhD, is a specialist in pain management at Children’s Hospital Boston and was involved in Cameron’s pain management. Also mentioned in the film are Taylor Lord, Cameron’s older sister by 2 years, and Eliza Lord, Cameron’s younger sister, born 3 months
before Cameron’s death. Hayden Lord, Cameron’s first cousin, also died of Tay-Sachs disease; his and Cameron’s fathers are identical twins. Hayden’s death occurred 5 months prior to Cameron’s.

*Cameron’s Arc* explores effective parent-professional communication across four critical points in the care of a seriously ill child. Each section explores one of these junctures in a way that is attentive to the family experience and is an opportunity for the pediatrician to act on a commitment to the patient and family. At these critical points in time, an unmet need is recognized, the need is understood and met by the timely provision of an appropriate resource, and the result is a deeper connection between the parents and doctor. It is helpful to consider the video in relation to each of these critical points, reflecting on how you might approach these moments yourself.

The relationship between doctor and parents in this story is characterized by open, respectful, and empathetic communication and overt compassion throughout the child’s fatal illness. Dr. Goldstein’s warm presence, humanity, and attention to the details of care for this family are a model for the care that most determined and compassionate community pediatricians can achieve; he had no specialized training to accomplish the exceptional care he provided—he was merely guided by compassion, competence, and a willingness to stretch himself to be the physician this family needed. We provide this film in hopes that his care will inspire you to be the doctor your patients living with life-altering conditions and their families need you to be. As you watch the film, please make mental notes about the following major elements incorporated into the medical home and models of palliative care. Palliative care is a paradigm that addresses deep-rooted problems for our sickest patients. It aims to relieve suffering, improve the child’s quality and enjoyment of life while helping families adapt and function during illness and through bereavement, facilitate informed decision-making by parents, families and health care professionals, and assist with ongoing coordination of care among clinicians and across various sites of care.

While you watch this video, consider:

**Breaking bad news**
How, when, where, and with whom was it said? What was said? What was not said? What were the specific words used and how did they affect the parents’ reactions?

**Providing disease-informed anticipatory guidance to a family with a medically fragile child**
What did the parents want to know? Were their needs met? Was there a mutual understanding of the goals of care? If so, how did that occur? Was it a one-time conversation? Was it a changing/evolving construct and process?

**Appreciating the importance of suffering and pain and its management**
How important was it to this family that their child did not suffer? What was done to manage symptoms before they happened? What was done to manage symptoms
when they happened? What resources were available to help the community physician manage symptoms?

**Defining a full life for a seriously ill child**
Was Cameron allowed to live a full life, as her parents envisioned? When does end of life begin? When should palliative care begin? Is palliative care the same as stopping treatment?

*Start the video. After viewing, it is recommended that learners be given a brief (2 minute) break to process the information and their reaction to it. Resume discussion following the break.*

**Questions for Discussion**

**Breaking Bad News**

_Rick: I made the diagnosis in my office and Blyth collapsed and Charlie was holding her. I left the room to give them time to be alone and then I cried in my office. I wanted to give them time, so I focused in on what we had to take care of. You don’t want to be detached and clinical._

1. What can you do to prepare yourself for such a conversation?

2. How would you characterize the way in which the Lords were informed of Cameron’s diagnosis? What do you notice about the pacing and delivery of the information? What was helpful to the parents about how the information was provided? Did Dr. Goldstein seem to be intentional in the way he structured the timing, environment, and wording?

3. What do you think about leaving a room to allow parents to be together after receiving a devastating diagnosis? What are the dangers and responsibilities that go with that?

4. How do you share control with the parents without abdicating responsibility, losing their respect, and demeaning your medical expertise?

5. How long-lasting do you imagine the effect of the initial informing interview to be?

6. How might personal cultural and spiritual needs be different for different families? How might you better understand the unique cultural and spiritual concerns of your patients and their families in these situations? How might that inform how you deliver difficult news?
7. Do we need to provide families with concrete avenues of hope? What help is available to you to do that?

8. What are your greatest fears in encountering families at the time of diagnosis when the patient has a serious illness and may die?

9. What do you or can you do to take care of yourself after such a draining experience? Is it OK to cry? Why or why not, and in what circumstances?

**Anticipatory Guidance**

_Blyth:_ Rick’s comfort with talking openly is what mattered more to us than if he got it right. It is clear that he was trying to do both. Rick was critical to our survival in many ways, and part of that was that it was important that he acknowledge the pain. It’s about being a healing presence—you don’t always need words.

_Rick:_ The degree of uncertainty in other cases unlike Cameron’s, without a firm diagnosis and clear outcome, often leads to unanswered questions. How do you advise such families when trying to provide anticipatory guidance? This plays a role in family frustrations, which, if not addressed head-on, can lead them to change care teams, with resulting discontinuity of care. It is a bit easier in cases like Cameron’s, in which early and certain diagnosis is possible, providing the opportunity to anticipate her course. However, in all cases of managing a childhood life-altering illness with a family, it is an uncertain journey and we have the privilege and honor of being companion, guide, participant, and learner, all at once.

_Blyth and Charlie:_ We are struck by the number of families not talking about what is going to happen next and how to deal with that. Families take different approaches to keeping the child alive for as long as possible versus quality of life driving the decisions. However, the families need accurate information if they are to truly have the opportunity to let their values guide the decisions they make. This requires open communication and clear anticipatory guidance, with acknowledgment of uncertainty where it exists and a willingness to provide new information as it becomes available. This is an uncertain path for all involved and we need to provide mutual support to each other.

10. What interactions with health care professionals contributed to the Lords adapting so successfully to their heartbreaking situation?

11. What do you observe to be the greatest sources of stress for Cameron’s family? What are some possible mitigating factors at your disposal to ameliorate these concerns? What obligation do pediatricians have to address the needs and concerns of the parents themselves as opposed to the patient only? Of the non-patient siblings?
12. What socioeconomic factors might impact families of dying children? What resources are available to help families with these needs?

13. How prepared are you to provide coordination of care? What is the responsibility of the primary care physician to involve specialists?

14. What future learning opportunities would you need to feel comfortable with coordinating care? What did Dr. Goldstein do to protect himself while providing effective continuous coverage for Cameron’s family? Was he overly involved, in your opinion?

15. What personal resources did the families use to help themselves? What seemed to help the most? Does it help for members of the health care team to point out the family’s own likely resources, to remind them of their base of support?

16. What is the difference between religion and spirituality? What role did either play in the capacity of this family to adapt to its circumstances?

**Pain and Symptom Management**

17. How important was symptom control to Cameron’s family? Do you think this is typical?

18. Do you feel prepared to manage symptoms effectively? Is it possible to anticipate symptoms and provide medication to manage the symptoms in advance of their occurrence? Who or what is available to assist you with that?

19. What other symptoms besides pain contribute to suffering? Are there non-physical aspects to suffering?

20. How might you assess for suffering in patients who have cultural and spiritual practices different from your own? How might you meet their needs within your community?

21. What is the relationship between pain and suffering? How does reducing the worry about pain reduce the suffering?

**Living a Full Life**

22. Is it the doctor’s job to help the family come to see that the dying child has lived a full life?

23. How do you feel about not providing all possible life-sustaining measures if a child could live a few weeks longer with a simple intervention, such as antibiotics or intravenous fluids? Where do you think the balance of authority lies in making such a decision, with the doctor or the parent?
24. How might a family's socioeconomic or racial/ethnic background impact care at end of life?

25. What benefit is there to having a child die at home? What are the problems with dying at home?

26. How can you prepare yourself and the family for the unpredictable course of dying?

26. When a patient dies, what do you do to help the team that has helped you provide care? What do you do for yourself?

Rick: When Cameron died, everyone was there. It was a very tranquil feeling, and as the doctor, you have to call the morgue, fill out death certificates, and you don’t want anyone else to worry about it. I cried on my way home and with my wife. You titrate yourself and learn how much of your stuff can fill the room and you find another place for it.
Additional Resource

The Courageous Parents Network Provider Portal offers free digital resources, including parent and provider videos, to support providers caring for children with serious illness. The Resources are available as short learning experience organized around:

- Conversations: Context and scripts to prompt important, and often challenging, discussions (e.g., delivering the diagnosis, introducing palliative care, supporting the non-patient siblings, advance care planning, and supporting families in bereavement)
- Shared Decision Making: Support for choices that work with family goals and values (e.g., feeding tube)
- Educating Self and Colleagues: Team discussion guides and exercises
- Family Resources: Downloadable materials developed by families, for families

Selected Bibliography

Pediatric Hospice and Palliative Care


Communication


**Pain and Symptom Management**


**Culture and Spirituality**


**Child and Family Perspectives on Serious Illness and Grief**


**Self-care**


Supplemental Materials

**What Is Hospice?**

*Revised from Marcia Levetown, MD, HealthCare Communication Associates, Houston, TX*

1. **What is hospice?**

Hospice is a package of services delivered to qualified patients by a group of health care professionals who work as a team.

Team members include

- The patient and family
- The patient’s physician and the hospice physician to provide medical supervision
- The hospice nurse, who visits a minimum of once every 2 weeks, but generally much more often, especially as the illness gets worse, to attend to symptoms and general well-being of the patient and family
- The hospice social worker, who helps with relationships, financial and funeral planning, and visits once every 2 weeks or more
- The patient’s chaplain and/or the hospice chaplain as desired, to attend to spiritual issues
- Home health aides, who assist with bathing, wound care, and other needs
- Volunteers, who provide companionship and sometimes assist with chores or amusing children who are involved in the situation
- Bereavement specialists, who assist with the management of loss, before and after the patient’s death

The focus of hospice care is the care of the patient AND the family, with attention not only to physical symptoms but also relationships, practical assistance and planning for the future, the pain of loss, and spiritual pain. Care providers are always on call, available 24 hours a day, 365 days a year. Bereavement care is provided for 1 year after the death of a patient.

2. **Who qualifies for hospice care?**

Patients with an expected survival of 6 months or less qualify, regardless of age or diagnosis. Another way to say this is, if your physician would not be surprised if you would not be alive in 6 months, even with excellent medical care, you qualify. A doctor has to certify this status, but you and your family can ask about the prognosis and whether you qualify for hospice. Patients qualify for care regardless of the ability to pay; only some hospices are committed to serving patients who cannot pay. Generally, these are not-for-profit hospices.

Some hospices will admit children from the time of diagnosis of a potentially life-threatening illness or condition, if life expectancy is confined to childhood. This is due to the fact that it is so hard on families to have a dying child because the families are young and often have few resources and other dependent children. Most children who die when older than 1 year of age die of trauma and are rarely referred to hospice programs. Patients with uncertain prognoses are also
rarely referred; however, if the patient is recurrently admitted to the hospital with life-threatening events, such as requiring mechanical ventilation or having sepsis syndrome, they have a short life expectancy, regardless of underlying diagnosis, and can very reasonably be referred to hospice. If the child does not die in 6 months but is unchanged, he or she is still hospice appropriate and can be maintained on hospice care.

Some hospices will not admit children; all hospices welcome the active participation of the pediatrician in the care of the dying child. Ask if they can provide a nurse, social worker, and chaplain who are experts or at least comfortable with the care of children.

3. What is included in hospice care?
Everything related to the terminal diagnosis is provided for patients who have insurance, including Medicaid or Medicare. This includes medication; equipment such as hospital beds and bedside commodes; any tests needed to understand the cause of new symptoms; anything in addition to medicines needed to treat symptoms; and the professional time of the team of caregivers from hospice and volunteers. Bereavement support continues for 13 months after death, but can be supplied in a variety of ways and is rarely focused on the loss of a child and the associated needs of parents and siblings. Patients without a payment source receive the care of the team and volunteers at no charge, but are asked to purchase the medicines and rent the equipment themselves. Donations assist hospices to provide these things when the patient has no way to obtain them. When patients have other health care problems other than the terminal diagnosis, the usual sources of payment are unchanged.

4. Where is hospice care provided?
Hospice care is provided wherever the patient is located, usually in the home or nursing home. It is also provided in personal care homes. Short-term stays in the hospital are available for difficult-to-control symptoms. Very few hospices have their own facility; in other words, you don’t “go to a hospice” like you go to the hospital. Hospice care services are provided in the home 95% of the time in the United States. Other countries provide a more palliative form of hospice, with respite, symptom control, and case management as the primary goals.

5. What is the advantage of hospice care compared with home health?
Hospice care is a partnership between the patient, family, and hospice team. Care is designed to attend not only to the physical realm, but also to the difficult feelings and issues that come with facing death. It focuses on the needs of the patient and the family. Home health, on the other hand, generally considers only the patient and only the physical symptoms. Patients and families are left to find providers of medical equipment and medications. In hospice, it is one-stop shopping. We coordinate your care with you. A single, fixed payment is provided by governmental payers (Medicaid and Medicare) to include everything you need. Currently this rate is about $140 per day.

6. What is the disadvantage of hospice care?
While all-inclusive, patient- and family-centered care delivered in the home is what we would all like to have, only patients with a 6-month prognosis for survival qualify. Often, this acknowledgment of prognosis is difficult for physicians and families alike, especially when the patient is a child. However, the biggest lament of families is that they got hospice care too late.
Referral to hospice is not “giving up”; on the contrary, it is providing additional, community-based resources for patients and their families.

Another problem is that hospice care is reimbursed at a rate that makes some very appropriate therapies difficult to pay for and keep the doors of the hospice open. This restriction does not occur in home health, which is paid for piece by piece. If the patient is a Medicaid patient, he or she may need to give up certain benefits that the state provides if they switch to hospice (eg, supplemental feedings, nursing hours). This varies by state and it is important to check before recommending hospice care.

7. Are all hospices the same?
No! Just as doctors and hospitals are different, so are hospices. Things to check are the number of children they have cared for in the last year, the pediatric training of their personnel, the number of patients each nurse and social worker are responsible for, the frequency of visits, whether it is not-for-profit, and where the headquarters are located.

8. What is Concurrent Care?
Fundamentally hospice is a health care and insurance benefit. In adult care, patients receiving the hospice benefit must resign curative, disease-directed treatments. Provisions of the Affordable Care Act and legislation in several states assure that this is not the case in pediatric patients. Parents are not required to forgo disease-directed care in order for their child to receive home-based, end-of-life hospice support.