



Ann F. Schrooten & Barry P. Markovitz

# SHARED STRUGGLES

Stories from Parents and Pediatricians  
Caring for Children with Serious Illnesses

 Springer

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Stories from Parents and Pediatricians  
Caring for Children with Serious  
Illnesses

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*Dedicated to Jack. May his memory always  
be a blessing.*

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## Foreword

My mentor in palliative care fellowship once told me that most of what we do as palliative care providers can be summed up as helping the hospital learn and understand what is going on in the patient's room. By "the hospital" he meant the whole panoply of medical and psychosocial care providers assigned to the patient, orbiting near and far from the bedside, anybody who might open up one of our consult notes to read the documentation of conversations in which we asked parents to tell us about their hopes and worries, about the sources of their strength and support, and most importantly, about who their child is, not as a patient, but as a person, because a parent's portrait of a child is a portrait of a parent's values and a family's values. By "the room" he meant not just the space enclosed by the four brightly colored walls, but the emotional and spiritual milieu in which the patient and family lived, loved, and hoped—the ordinary physical space being a metonymy for an extraordinary metaphysical space that housed not just the bodies of a patient and their family, but also their stories and their spirits.

This book is an exquisite collection of just that kind of story. To read it is to learn just how much goes on inside "the room," just how rich and terrifying and beautiful any one family's experience of the hospital can be, how totally different every family is in their unique phenotype of daily struggle and triumph, how very much the same they are in the example of profound loving they make to us all.

But this book collects the story of what is going on in another room, one that intersects and overlaps with the physical and metaphysical spaces of the patient's room. The doctor's room is a workroom on the unit, but also the empty storeroom into which they might retreat to collect their thoughts and feelings, or the car in which they make their commute, and like the patient's room, the doctor's room expands to encompass their home, their own family, their friends. It is the head-space and the heart-space in which they attend to the patients and families under their care.

To collect and juxtapose these stories is already to make something beautiful for the world at large and useful for the community of care for children with serious illnesses and their families. But *Shared Struggles* takes the risk of committing itself to reconciling these stories, by means of parent and physician commentary which engage with the content from positions of equal and complimentary expertise. That risk elevates the beauty and use of the book such that it becomes something entirely astonishing and necessary and completely one-of-a-kind: a textbook of connection

between physician and patient and family, one that illustrates in real time the process of reconciliation between the lived experience of each party, a reconciliation that is the fundamental act of pediatric medicine.

As pediatric medical providers, we talk about the art of medicine as something we practice upon patients, not often recognizing that patients and families, and parents especially, practice their own art of medicine, not on their children or themselves, but upon us. They are called to manage us, in the course of their child's illness, just as much as we are called to manage their children, as they partner with us in loving care, seeking always to find a way to accept the help we offer while protecting their child from any harm we might do. You cannot tell someone how to practice such an art any more than you can tell them how to be compassionate, or empathetic, or kind. But that does not mean instruction is impossible. Such attributes, and such art, can be fostered and encouraged into sturdy practice. You cannot simply tell someone how to make a genuine connection with their patient, how to shape their professional boundaries, not as lines in the sand, but as contours along the heart. You cannot just tell someone how to balance advocacy for their child with trust for a provider, how to put faith in the love of a stranger for their child and never lose faith with oneself. But you can certainly show them how to do it, as this collection shows us, with unparalleled richness and sincerity, over and over again.

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## Acknowledgments

When the idea of what we wanted this book to look like was solidified, we knew the people we needed to make it happen – the parents of medically complex children and the pediatricians caring for these children – were exceptionally busy people. Asking parents deep in the trenches of caring for their child and physicians overwhelmed with patient and academic responsibilities to take the time to write a story for this book was, admittedly, an intimidating endeavor. We reached out to our respective networks of parents and colleagues not knowing what to expect, but hoping for the best. The response we received was overwhelmingly kind and supportive. As the book took shape and the areas we wanted to focus on became clearer, we were limited in the number of stories we could include. As a result, we were unable to include all of the stories we received. The contributors listed are those whose stories are included in the book; however, every story that was contributed was instrumental in the making of the book. Every person who contributed a story validated the importance of the book and every story and lesson shared was carried with us as we wrote our commentaries. Thank you to each and every person who contributed a story for giving your time, your heart, and your insight to make this book the unique and valuable resource it is.

Thank you also to the people who graciously gave their time to review drafts, provide feedback and edits, and supported us throughout the process from beginning to end, especially Bridget, Kathie, Jenni, and Erin.

Finally, thank you Jack for being the thread that connected us. You are a beautiful soul who taught us all so much without ever speaking a word.



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# Contents

**Part I    Compassion**

**1    What Matters at the End . . . . . 3**

**2    I Did Not Have to Fix It . . . . . 9**

**3    No Wrong Decisions . . . . . 13**

**4    Reuniting Families . . . . . 19**

**5    Leading with Compassion . . . . . 23**

**6    Minute by Minute, Step by Step . . . . . 27**

**7    Seek Permission First . . . . . 31**

**8    A Sacred Relationship . . . . . 35**

**9    Kids Like These. . . . . 39**

**10   A Smile Worth Saving. . . . . 43**

**Part II    Trust**

**11   Team Harlie . . . . . 51**

**12   Best Laid Plans . . . . . 57**

**13   If We Are Paying Attention . . . . . 61**

**14   Full Disclosure. . . . . 67**

**15   The Photograph. . . . . 73**

**16   Learning Together. . . . . 77**

**17   Altered Path. . . . . 83**

**18   The Befores and the Afters. . . . . 87**

**19   Not Everyone Is Born a Superhero . . . . . 91**

**20   Beyond the Numbers. . . . . 95**

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<b>21</b>	<b>Shared Experience</b> . . . . .	<b>101</b>
<b>22</b>	<b>Tying the Thread into a Bond</b> . . . . .	<b>105</b>
 <b>Part III Communication</b>		
<b>23</b>	<b>A Voice That Doesn't Use Words</b> . . . . .	<b>113</b>
<b>24</b>	<b>Brave the Difficult Conversation</b> . . . . .	<b>119</b>
<b>25</b>	<b>A Roadmap</b> . . . . .	<b>123</b>
<b>26</b>	<b>Teamwork</b> . . . . .	<b>129</b>
<b>27</b>	<b>Relearning to Listen</b> . . . . .	<b>135</b>
<b>28</b>	<b>Words Matter</b> . . . . .	<b>141</b>
<b>29</b>	<b>Trust Their Voice</b> . . . . .	<b>147</b>
<b>30</b>	<b>Knowing Your Family</b> . . . . .	<b>151</b>
<b>31</b>	<b>Advocacy Is Not Anger</b> . . . . .	<b>157</b>
<b>32</b>	<b>Where Is the Doctor?</b> . . . . .	<b>161</b>
<b>33</b>	<b>Failure to Communicate</b> . . . . .	<b>167</b>
<b>34</b>	<b>When a Patient and Family Forever Change Your World</b> . . . . .	<b>173</b>
<b>35</b>	<b>Respect: A Two-Way Street</b> . . . . .	<b>181</b>
 <b>Part IV Hope</b>		
<b>36</b>	<b>Persistence of Hope: A Story in Two Acts</b> . . . . .	<b>189</b>
<b>37</b>	<b>Can I Offer You Advice?</b> . . . . .	<b>195</b>
<b>38</b>	<b>The Life of the Party</b> . . . . .	<b>201</b>
<b>39</b>	<b>Every Single Second Worth It</b> . . . . .	<b>209</b>
<b>40</b>	<b>Partners in Hope</b> . . . . .	<b>217</b>
<b>41</b>	<b>Answers for Rosie</b> . . . . .	<b>223</b>
<b>42</b>	<b>We Treat Souls, Not Just Bodies</b> . . . . .	<b>227</b>
<b>43</b>	<b>Never Give Up</b> . . . . .	<b>231</b>
<b>44</b>	<b>The Sliver of Sky</b> . . . . .	<b>237</b>
<b>45</b>	<b>The Many Voices of Hope</b> . . . . .	<b>243</b>
<b>46</b>	<b>Mothers Club</b> . . . . .	<b>249</b>
 Glossary . . . . .		<b>255</b>
 Index . . . . .		<b>257</b>

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## About the Editors

**Ann F. Schrooten** and her husband, Mark, are parents of four children. Their son, Jack, was born with a rare congenital muscular dystrophy that affected his muscles, eyes, and brain. Jack required the support of a ventilator to help him breathe; he was non-verbal, non-mobile, and required round-the-clock care. Yet, despite all his challenges, Jack woke up every morning with a smile on his face and eyes that sparkled with the anticipation of a new day. Jack lived a love-filled life until his death at the age of 15. Ann has experienced hundreds of encounters with doctors and other medical professionals, beginning with Jack's premature birth and complicated first year where he spent many months in the Pediatric Intensive Care Unit, through his diagnosis odyssey, the many procedures, surgeries, and hospitalizations he endured, his transition to palliative care and, finally, to hospice care at the end of his life. Because of Jack, Ann has connected with a large network of other parents of medically complex children from across the country and the globe. She is the founder of The Willow Tree Foundation, an Arizona non-profit organization that funds respite for parents of medically fragile children (<http://willowtreefoundation.org>). She also created TouchStones of Compassionate Care®, a program that promotes compassion in the delivery of healthcare. ([www.touchstonesofcc.blogspot.com](http://www.touchstonesofcc.blogspot.com)). She lives in Chandler, Arizona, and enjoys writing, kayaking, and hiking.



Dr. Barry Markovitz and  
Jack Schrooten

**Barry P. Markovitz** earned his Bachelor of Science degree at Washington & Jefferson College in Washington, Pennsylvania, and his medical degree at the University of Pennsylvania. He completed his pediatric residency at Children's Memorial Hospital in Chicago (now Ann & Robert H. Lurie Children's Hospital of Chicago) and a residency in anesthesiology at the Hospital of the University of Pennsylvania. Following his fellowship in pediatric anesthesiology and critical care medicine at the Children's Hospital of Philadelphia, he then joined the faculty at Washington University School of

Medicine in 1990 and was an attending pediatric anesthesiologist and intensivist at St. Louis Children's Hospital. He moved in 2006 to become the director of critical care medicine and medical director of the PICU at Children's Hospital Los Angeles (CHLA) and is a professor of clinical pediatrics and anesthesiology at the University of Southern California Keck School of Medicine. In 2018, he became the chair of the Department of Anesthesiology Critical Care Medicine at CHLA.

He has a strong interest in medical informatics and has been the editor of PedsCCM: The Web Site for Pediatric Critical Care Medicine (<http://PedsCCM.org/>) since its inception in 1995. He was a co-founding member of the Virtual PICU and was the chair of the scientific review committee of VPS, LLC. His interest in evidence-based medicine and clinical epidemiology involves editing the Evidence-Based Journal Club on the PedsCCM website (nearly 1000 evidence-based reviews of literature in critical care) and completing a master's degree in public health at St. Louis University School of Public Health in 2003. He has been involved in the planning and/or conducting of numerous multicenter trials in pediatric critical care medicine and recently completed a term as the chair of the Scientific Steering Committee of the PALISI (Pediatric Acute Lung Injury and Sepsis Investigators; <http://palisi.org>) research network. He has authored or co-authored over 70 peer-reviewed publications, chapters, and monographs and given over 80 public presentations and lectures. Barry and his wife, Martha, have been married for 35 years and have two adult daughters. He lives in Los Angeles, California, and enjoys running, hiking, and reading fictionalized history books.

Ann and Barry met more than 20 years ago when Barry was one of the intensivists who cared for Ann's son, Jack, in the Pediatric Intensive Care Unit where he spent much of the first year of his life. Ann will always remember the first time she met Barry. It was early one morning in the PICU; she was sitting in a chair next to Jack's bed when he came over to talk to her about Jack. What she remembers is not what he said, but what he did. Before he said anything, he gently knelt down by the chair so that he was eye level with her rather than looking down on her when he spoke. This simple act was so impactful because it was the exception, not the norm. To most, this may seem like a meaningless, trivial gesture. On the contrary, Ann will tell you that it is indicative of the special person and doctor Barry is – he is humble, he is respectful, and he is kind. Four months after that first encounter, Barry would show up at Jack's bedside and offer to do something that was, again, the exception, not the norm.

When Jack was discharged from the PICU needing the support of a home ventilator, Barry offered to take on the unconventional role of managing Jack's care. The expectation was that Jack would only need the support of the ventilator for a short time and would quickly wean from it. After several years, when it was clear that Jack would need long-term ventilatory support, his care was taken over by a pediatric pulmonologist who specialized in the management of ventilator-dependent children. However, despite this "break" in the doctor-patient relationship, Ann and Barry stayed in touch over the course of Jack's life – Ann always seeking out Barry's advice and reason in connection with Jack's care, and Barry always willing to listen and help in any way that he could.

Barry's recollection of Jack and Ann in the early days did not seem particularly extraordinary. Jack was a patient and Ann was his mother. The lessons that Barry learned from them were simple and only later became generalizable. Ann knew Jack better than anyone. She paid attention to detail and could always be trusted to be Jack's best advocate. No one else on the healthcare team could do what she did. So Barry got "trained" early by Jack and Ann to listen to them – carefully – respect their concerns and address them. And even if there was not an immediate answer, he paid attention. Barry also learned that a diagnosis and a prognosis are, at best, educated guesses. Every patient is different and even with the same specific genetic mutation, each may manifest a condition differently. Finally, he learned that the often-vaulted "quality of life" – like beauty – is in the eye of the beholder. The only beholders that matter in this area are the patient and the parent.

Shortly after Jack's death, Barry pitched the idea of this book to Ann – who jumped on board without hesitation, eager to fill the void of Jack's absence and the unfamiliar free time she now had. This book was written and compiled over the course of 5 years, but its roots were planted over 20 years ago in a Pediatric Intensive Care Unit when a special connection was made between a little boy named Jack, his mom, and a doctor who agreed to follow a kid on a vent even though it was outside the box. While they never imagined where that connection would take them, it seems only fitting that it would lead to the unconventional bringing together of parents and doctors to share their personal stories and experiences in this first-of-its-kind book. They have learned a lot from each other over the years and are grateful for the opportunity to continue the conversation through this book and the honest and heartfelt stories told by both sides of the physician-patient/parent relationship.

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## Introduction

Respectful communication is really valued by parents of medically complex kids. Invite me into the dialogue and ask my opinion, or at the very least, respect my concerns. In our world, we have been forced to become experts in a field we did not choose.... I can see how a resident neurosurgeon wants to feel some respect for their years of grueling work to get where they are. But so do I.

—Parent

That moment of contact, of connection and real communication with this *person*, remains a pivotal moment in my career.... I always take care now to allow for space for children to express their voice, in whatever form that might take. To not expect that communication occur on my terms, but rather to be open to whatever terms and means of communication, no matter how subtle, a child might choose.

—Physician

There are approximately three million children in the United States living with complex medical conditions. With advances in medicine, this number will only grow as children born with rare and life-limiting conditions live longer. Children with medical complexity have chronic health problems that affect multiple organ systems and result in functional limitations, high healthcare needs, and often require the use of medical technology. The parents of these children become experts in their child's condition. They connect with other parents; they travel to world-renowned Children's Hospitals for second and third opinions; they ask questions; and they are relentless advocates for their children. In emergency rooms, ICUs, hospital rooms, and clinics, these parents spend a lot of time with the healthcare team and often interact with as many as ten or more pediatric subspecialists caring for their child. These interactions can often be filled with tension, misunderstanding, and conflict. Parents make assumptions about physicians (e.g., "He doesn't care." "She thinks I'm being difficult."), and physicians make assumptions about parents (e.g., "They don't understand their child's disease." "She's an angry mom."). On the other hand, there are also many instances of great compassion and understanding, and encounters where parents and physicians are deeply affected and changed by their interactions and relationships.

We know that stories are one of the most fundamental and effective ways to engage and teach our fellow human beings. This is the first book to share stories from both sides of the physician-patient/parent experience through richly detailed



and heartfelt stories contributed by parents of medically complex children with a wide range of disorders and diseases, and by pediatricians practicing in the many subspecialties that provide care to these children.

The parent stories are contributed by parents from across the United States. Each story emotionally describes an encounter or relationship with a physician that had a significant impact on the parent and their child. The parent stories share compassionate and positive physician interactions, as well as instances where their child's physician let them and their child down. To maintain anonymity, the physicians and hospitals involved are not identified by name and some parents have chosen not to use their child's real name. The physician stories are contributed by physicians practicing at many of the best Children's Hospitals throughout the country. These stories poignantly tell of encounters and relationships physicians had with their patients and parents that significantly impacted them and served as learning moments in their career. In those stories where the family's consent was not obtained, the names of patients and parents have been changed to protect privacy and patients have been de-identified. To further protect privacy, the parent and physician contributors are not identified with their stories.

Following each story are commentaries written by the editors; a parent commentary written by Ann, and a physician commentary written by Barry. The commentaries provide an independent perspective on the events and messages conveyed by the story contributor and are intended to encourage reflection, inquiry, and discussion. We understand and respect that we cannot truly put ourselves into the shoes of the storyteller, we can only draw upon our own experiences when sharing our perspectives and "take-aways" from each story. With respect to the physician commentaries – I (Barry) want to add that a time honored tradition in the medical profession is to not throw your colleagues under the bus. Perhaps too honored. Some of my commentaries may verge on a criticism of my unknown colleagues. I do not pretend to put myself in their place, as I cannot even fathom all the intricacies of issues they were dealing with at the time. And we have only one side of the story in most cases. However, as with possession and the law, perception is 9/10ths of reality. If these parents perceived a lack of empathy or proper communication on the part of physicians, that was their reality. Only now do we have the hindsight of the "retrospectoscope" – the ability to look backwards in time and suggest a different course.

We learn and change most from hearing stories that strike a chord with us. The parent and physician stories are grouped under four parts that touch on the universal themes of compassion, trust, communication, and hope, and will strike a chord with everyone who is on the giving and receiving side of healthcare. By giving a voice to both parents and physicians, and by listening and learning from their stories, we hope this book can be a bridge to better understanding between the parent expert and the medical expert and lead to improved communication, minimize conflicts, and foster trust and compassion among physicians, patients, and families. A strong partnership between the parent and the physician is vital to ensuring the best care possible for this unique and growing population of children.

Could a greater miracle take place than for us to look through each other's eyes for an instant?

*–Henry David Thoreau*

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## Part I

# Compassion

Compassion is not a virtue. It is a commitment. It's not something we have or don't have.  
It's something we choose to practice. —Brené Brown

# What Matters at the End

# 1

Summer was at its peak and so was the heat. Our beloved dog had just died and my husband and I were trying to distract ourselves by going for a walk in the neighborhood park. The familiar plethora of summer smells was filling the air—freshly cut grass, an early dinner cooking on a nearby grill, and the many hard-to-classify odors that come on waves of hot air in late July. I understand how morbid, strange, and even irresponsible it sounds, but it took the death of our dog to open my eyes to our son's suffering. I knew our youngest son was going to die. I had known for 2 years that due to faulty genes passed down by me and my husband, toxins were accumulating in his little body, progressively destroying his nervous system and spinal cord. We watched the disease ruthlessly claim his ability to sit, smile, see, and eat. With each reversed milestone, we became increasingly aware of the trajectory of his illness and intimately familiar with both his and our own suffering. Yet, the human heart has an amazing capacity to adjust and adapt and 2 years after the diagnosis, trained as it was to suffering, my heart had grown numb. I believe it took the death of our dog to crack it open again.

Two years prior, a few months after receiving Joey's diagnosis, we made the decision to have a gastrostomy tube (G-tube) placed into his stomach to give direct access for supplemental feeding, hydration, and medication. At that point, he was still nursing and able to eat pureed foods by mouth; yet, our medical team mindlessly followed the standard protocol of scheduling a consultation with a GI specialist, undoubtedly because our son's diagnosis included words such as "genetic," "degenerative," and "neurological." During the initial consultation, the GI specialist did a beautiful job explaining why Joey needed a G-tube, referencing risks of aspiration pneumonia, dehydration, and issues with administering medication. Her arguments in favor of a G-tube were presented as fact. Never once did she ask if a G-tube indeed was in line with our philosophy of care, nor did she mention what the alternative (no intervention) might look like. A couple of months later, during the preoperative huddle, we had another extensive conversation, this time with the surgical team regarding the risks and concerns around general anesthesia administered to a child with decreased neuromuscular function. No one, however, told us that

providing feeding and hydration through artificial means would likely extend life, that it could prolong the natural process of dying, and contrary to our goal of keeping Joey comfortable, could also add to his suffering. These were things we were left to learn through first-hand experience.

Back from our walk, guided by our hearts as opposed to an anticipated medical event, my husband and I realized we did not know the protocol—when to call or how to communicate to Joey’s medical team that the end was near. There was no medical emergency, we did not “need” them for anything, but we chose to reach out because we wanted them there.

Joey’s pulmonologist answered our call late on a Saturday afternoon in July. It was a short conversation. My husband informed him of how Joey had reached a new level of decline and that we were going to discontinue his feeds with the anticipation that he would pass in the next several days. My husband did not say that our hearts could no longer bear the pain of watching our son suffer, that keeping him alive by providing his frail little body with nutrition and his lungs with oxygen felt selfish and unkind, yet somehow the message still translated the same. Less than 24 hours later, on his way home from a family event, John walked through our front door. No white coat, no stethoscope, no hand sanitizer, or pulse oximeter in tow. He simply showed up as another guest in a house full of love-filled mourners.

By this point, we had long ruled out a miracle and any potential solution to the unfixable problem that a fatal diagnosis is. Instead, connection and the presence of others became the most vital and valuable gifts to us. Connection takes us deeper than job descriptions, titles, and formalities, but it needs to take its own shape and can never be forced or fabricated. It is comforting because of its authenticity. It cannot be achieved through a formula or a prescribed set of best practices; it can be as simple and profound as a pediatric pulmonologist, in civilian clothing, sitting on a couch with a glass of wine and his dying patient gently cradled in his arms.

Joey went 14 days without food and 10 days without water. Against all our parental instincts, yet fueled by pure, deep, and unconditional love for our son, not the opinions of our medical team, we were able to push our own needs aside and allow for what needed to happen. We simply had no clue how gruesome and drawn out death can be. Predictions around the number of days or hours he had left to live varied by the day and the conviction of the person assessing him. In hindsight, I would say those predictions are both empty and inconsequential. It is nearly impossible to predict the final breath. However, 14 days without sustenance both looked and felt like the definition of starvation, which was the opposite of what we hoped and prayed for. Two years of listening to the rattling in Joey’s little chest and the sound of secretions pooling in the back of his throat led us to believe he would die of pneumonia—that it would be “quick” and “peaceful.” We were wrong on both accounts.

Friday, August 11, 2017—a day etched on my mind and soul and likely in every cell and muscle fiber of my body, forever. The unforgiving August sun made our house feel small, airless, and muggy, causing me to pity the large number of friends, family, and members of Joey’s care team who were struggling to get comfortable in our tiny living room.

After listening to our lamentations about a seemingly endless ending, and perhaps in an attempt to protect our hearts and minds, Joey's neurologist reluctantly said, "Death isn't always peaceful. The final moments can be rather traumatic for the ones having to watch their loved one die." He went on to explain how air hunger and terminal agitation appear agonizing, but are not uncomfortable for the dying child. His full-of-compassion-non-sugar-coated-hard-to-hear truth turned out to be a prophetic and considerate warning of our son's final hour.

The end itself was as sacred as it was excruciating. At 3:27 a.m. the following morning, our friends Scott and Susie, who had offered to take the night shift so Sam and I could get some sleep, let us know Joey's breathing had changed and that we should probably come and get him. When Sam brought him into our bedroom, Joey appeared to be in deep distress, frequently gasping for air as his face gradually changed color. For 10 minutes we watched as our son's body shut down until eventually the breathing stopped all together and he died, not so peacefully, in my husband's arms.

There is nothing more basic to parenting than to feed your child, and there is nothing more painful than mercifully denying your child sustenance. Even though Joey was unable to eat by mouth the last 18 months of his life, my desire to nurture him never subsided. The various combinations of oats, quinoa, avocado, veggies, fruit, peanut butter, prunes, coconut oil, beets, and apple sauce I ran through our Vitamix blender every day undeniably made some part of me feel better, but I think it benefitted him as well. And no, we did not agree to our son's G-tube surgery because we had to or were forced to, no one is. We did it because it felt like the right thing to do. Joey never learned to drink out of a bottle and, as a result, dehydration and, eventually hunger, did indeed make him and everyone around him miserable.

Our decision to provide nutrition through a G-tube unquestionably brought comfort and improved everyone's quality of life, but a conversation about the end and what it could look like would have prepared us and saved us from unnecessary self-doubting, questioning, and pain. Also, after 14 days of watching his already frail little body waste away, I wish someone had reminded us that Joey's death did not occur from starvation or dehydration, but that the underlying condition, a fatal genetic disorder, ultimately took his life.

Initially fueled by frustration and desperation, my husband and I advocated hard for our youngest son. We questioned the benefit of certain tests and therapies. We demanded more frequent and better communication. When Joey's doctors avoided difficult topics and conversations, we threw the lasso and reeled them back in with raw, honest, and sometimes unsolicited comments. We are grateful for Neil, Joey's neurologist's insight and courage to address a difficult topic at a most difficult time. Without him, Sam and I would have been ill prepared for a traumatic, but normal death. His willingness to work through discomfort and pain made for deep trust and came to serve as the cornerstone in all our communication and interactions. The same holds true for John, Joey's pulmonologist. His humility, compassion, and ability to embrace our pain as well as his own helplessness opened our eyes to the importance of connection. Connection makes the lonely feel seen; it fuels the weary and it is the vehicle that takes you from shock and

denial to acceptance and surrender. Connection is more important than your ability to fix someone else's problem or take their pain away.

In the end, it was our trust and connection with John, Neil, and the many other providers, not their knowledge and expertise, that ensured a sacred ending to our son's full and beautiful life.

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## Parent Commentary

This story speaks to the extraordinary relationships we develop with our child's doctors. When our child is born with a life-limiting condition, there are those doctors who will be with us throughout our child's life. It may be the neurologist who follows the progression of our child's disorder or the pulmonologist who manages our child's ventilator or fragile lungs. It may be the palliative care doctor who becomes part of our team at the time of diagnosis or comes on board when we realize that our child's health is declining as a consequence of his underlying disease. There can be no closer relationship with a doctor than when he or she walks with us through our child's diagnosis, disease progression, decline in health, and, ultimately, our child's death.

When we receive a devastating diagnosis for our child, our first reaction is that we want a doctor to fix it. Before entering the world of life-limiting and rare diseases, we always believed that when your child is sick, you make an appointment with the doctor, the doctor applies their knowledge and experience, writes a script, and your child gets better. This is the world the majority of parents live in. It is shocking for a parent to hear that their child has a disease that cannot be "fixed" and will eventually take their child's life.

There is much that doctors can do for our children over the course of their lives. They resolve acute issues, they manage their extensive and ongoing needs to keep them stable, they ease their pain, and they help us give our child the best quality of life possible. However, what can doctors do when our child's disease progresses to the point where there is nothing more medically that can be done to delay our child's inevitable death?

They can show up.

The two doctors in this story showed up in extraordinary ways. There was nothing more they could do for Joey, but they showed up for his parents. They stepped out of their own comfort zone to come into a dying patient's home. While they came into Joey's home medically empty-handed, what they brought with them instead was great compassion. By showing up, they let Joey's parents know that Joey's life mattered to them. They honored the strong connection Joey's parents felt toward them and validated Joey's parents' trust in them. They helped make getting through the impossible possible. The power of trust and compassion cannot be overstated.

When there is nothing more medically a doctor can do for their patient, there is still so much they can do. Doctors can listen, offer words of comfort, answer questions, and simply be there for the family. While not all doctors can (or are even invited to) show up in person at a patient's home, they can still be there—by making a phone call or by sending or responding to an email. Doctors can continue to walk the walk with their patient's family until the very end.

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## Physician Commentary

This is an extraordinary journey, relayed with great self-insight and compassion. I would like to comment on three themes. In the first, this mother seems to suddenly come to the realization that her son was suffering. This is heart rending. When physicians try to outline what a child's life will be like with a progressive, neurologic disorder, at least while the child (as a baby) still appears pretty normal, this message is hard to hear. It is difficult to believe that the compassionate physicians described here did not, earlier on, try to prepare this family for what the disease progression would look like. What suffering would look like. But often we are not heard, or, as in other stories in this book, we are told we are not offering enough hope. This is an extraordinarily fine line to walk for physicians. Tell the truth but do not take away hope. In the end, every family is different and sees their child differently. It is truly up to the family to decide the path they take, as long as they are armed with the best evidence possible.

The second issue here appears to be the lack of palliative care support. This field in Pediatrics remains understaffed in many places around the country, but a multi-disciplinary palliative care team could have made the last weeks and days of Joey's life so much less distressing to him and the family. It sounds like this family was just on their own, and this should not be happening in our society today.

Finally, for many physicians, when they have nothing else medically to offer, they may instinctively pull back, at least emotionally. Although we try to avoid these terms today, but to lose a patient means to have failed, at least to some. No matter the disease or lack of treatments, many physicians still take the death of a patient as a personal failure. It is supremely hard to show up in the face of failure. I admire the physicians in this story who did show up at the end, perhaps not even realizing what their presence meant to the family. They showed up because they cared and were likely able to suppress the emotional burden on themselves. Physicians do need to put up some walls to protect themselves, but the truly skilled ones can find an opening in the wall, to drop their armor, and be present when it matters most.

## I Did Not Have to Fix It

# 2

I met Alex when he was 2 days old. He was one of twins who, as many twins do, was born prematurely. Alex's brother died soon after being born. Alex endured many of the complications that come with being born prematurely—he had lung problems, he had vision problems, he had hearing problems, he had feeding problems, and he had liver problems. Alex's brain had been damaged by lack of oxygen and a hemorrhage, and as commonly seen in those circumstances, Alex had epilepsy and cerebral palsy.

Alex spent the first 6 months of his life in the Neonatal Intensive Care Unit. In the beginning, there were days when he was close to dying. "He is a fighter," people used to say, as if being ill, or even dying was only for losers. As time went on, Alex stop needing a machine to help him breathe, he then stopped needing to be fed through his veins, and his liver function became stable, if only his brain had kept up with the progress.

Alex's mother was doggedly determined to give her boy every opportunity to go beyond surviving. She did not *just* take care of him, she was an unyielding, even obstinate, advocate. There was no stone she was going to leave unturned. Her assertive advocacy rubbed some clinicians the wrong way. After going through several neurologists, Alex's mother settled on me. I told her that she had a penchant for tall bearded doctors. She just laughed.

Initially, I saw Alex and his mother about every 3 months. As per protocol, the first series of visits were scheduled for 30 minutes. But soon I learned that 30 minutes was not enough to even get over the greetings. Alex's mother always came with a long list of concerns; only a handful were related to my area of expertise. From rashes, to unexplainable movement. From drooling, to naughty behavior. The kid was 6 months old, what kind of naughty behavior can a child his age have?

Alex's clinic visits went from 30 to 60 to 90 minutes in length. Eventually, I gave up trying to predict how long the encounters were going to be and started scheduling Alex at the end of the day. I would much rather stay at the clinic late than make my other patients wait. And so it went that some visits lasted over 2 hours. What did we discuss? Everything. Alex's health of course, but also stories about Alex's sisters, his



mother's trials to get Alex services and resources, and even politics (done so against conventional wisdom). Then there were those instances where I did not do anything other than listen. The visits ended when Alex's mother decided it was time to leave.

Alex's mother and my relationship had its ups and downs. There were times when I had to remind her of our agreement—I would always be honest with her, no sugar coating, the unadulterated truth. Alex had a permanent brain injury, and while the injury was not progressive, the consequences were. In some of those instances, Alex's mother would become irritated. She would come back and say, "If Alex could only break out from that crumpled body of his, you would see. No more seizures, no more feeding tubes, no more wheelchairs." Those squabbles would be followed by long periods where I would not see Alex. His mother took him to see clinicians at other institutions, some of which I had recommended. Then, for no evident reason, I would find Alex on my schedule. No explanations were necessary. His mother and I would pick our relationship up exactly where we had left it. Like two old friends.

Alex went from a cute little baby to a budding adolescent. He kept *graduating* from one wheelchair to the next size up. Yet his mother insisted on lifting him from the wheelchair and placing him on the examining table all by herself. Once I tried to help, and backed off lest I have my wrist slapped.

As Alex grew, so did his family. I do not know where his parents found the bravery to have two more children. At each visit, I learned something new about the four girls. Grace, the oldest, started middle school, while Rose, the youngest, was in first grade. Alex's mother shared with me pictures from birthdays and vacations, and I always received a Christmas card.

Alex was a personality. I once saw him on the local evening news paying respect to a fallen law enforcement officer. On the day of his death, the police department of the suburb where Alex lived made him an honorary policeman.

Alex died on an ordinary January day. He fell prey to the flu. One of his sisters brought the virus home from school and soon thereafter, every member of the household was running a fever and sneezing. Alex became acutely ill and was soon admitted to the intensive care unit. But his body was tired. He had been battling all sorts of maladies throughout his life and had finally met his match. Alex's parents wanted the family to send him off in the manner in which he had lived. His mother gave the young man a sponge bath with the assistance of his sisters. Then everyone stood by Alex's bed and had pictures taken. Eventually, Alex's nurse placed him in the arms of his mother and the tube that tethered him to this world was removed.

Starting with medical school and continuing with residency and fellowship, physicians are taught to mend broken bodies. We prescribe medications and do surgery to fulfill our role of healers. To an extent, it is a role with which we are comfortable. Every so often, however, we are asked to take on roles which can make some uncomfortable—listeners, confidants, and consolers. Alex's mother challenged me, and by doing so she made me a better physician. She wanted me to continue performing the responsibilities of healer, as she simultaneously persuaded me to become a member of the family, even if a distant one. What a privilege. A stranger who happened to have been on call the day that Alex was born was invited into a family in pain's ambit.

Alex's wake took place on a miserable winter day. It was cold and snowing. On my way there I called my wife and told her "I will get there, pay my respects, stay for a few minutes and leave. Half-an-hour at most. I'll make it back for our dinner reservations." Boy was I wrong! The line to see Alex snaked through every room of the mortuary—and it was moving slowly. "It will take me an hour tops," I thought "No problem with dinner." Two hours later I called my wife again, "Cancel the dinner plans" I said.

I was finally able to enter the room where Alex was resting. Alex's parents each gave me a hug, and his mother called me "my love." I told them what an honor it had been to be Alex's neurologist. What a privilege it had been to know their family for over 10 years. What a joy it had been to see the girls grow up. As I looked at Alex in his coffin, I recalled the instance when his mother told me "If Alex could only break out from that crumpled body of his." She was right. Alex's body was no longer crumpled. He was resting with composure and dignity.

"Thanks so much for coming to say goodbye to Alex," his mother said. "I can't tell you how much the visits with you meant. I realize I asked you many questions that had nothing to do with neurology, and yet, you always obliged. But most of all, I appreciate that you were willing to listen, to become part of our family, and that you did not feel compelled to try to *fix it*."

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## Parent Commentary

Admittedly, parents of medically complex children can be obstinate advocates and unlikeable at times. We are often referred to as "that parent." However, it is important to understand that we are unyielding because there are so many people we encounter who put up barriers, treat us as if we are clueless, tell us "no," and make caring for our child extraordinarily difficult. These people are not necessarily the physicians who care for our child. They can be the insurance company, medical equipment company, nursing agency, and school district. If we do not learn to be assertive and stand our ground, our child would not get what they need and are entitled to. It is not personal; it is survival.

The physician who can form a bond with a parent who is fierce, stubborn, and difficult, and who recognizes that every emotion and action is directed toward our child's best interest, is a truly special person. The physician in this story exemplifies this. He is remarkably patient, compassionate, and humble. The bond between a parent and their medically fragile child is inexplicably different than the typical parent-child bond. We are one in the same with our child. Therefore, when our child comes under a physician's care—the physician not only cares for our child, he cares for us. This physician used his medical knowledge and skill to care for Alex; he used his heart to care for Alex's mother. He gave her comfort by listening to her and giving her an extraordinary amount of his time. And he maintained her trust because he was always honest.