



INTRODUCTION:

Unexplored Territory

I have found the best way to give advice to your children is to find out what they want and then advise them to do it.

—Harry Truman

Debbie's Story

Megan's mom was always there—in the waiting room during clinic appointments and at Megan's bedside when she was hospitalized for problems related to the multiple sclerosis that was diagnosed 18 months ago. We could always depend on Megan's mom. She told the nurses and doctors things that helped them plan care for Megan, like that ever since Megan was a little girl, her stomach felt better when she had ginger ale—at room temperature, and only in a glass, never the can. Megan's mom was so dependable. She picked up Megan's prescriptions and her kids from soccer practice. She dropped off the dry cleaning and cookies for the clinic staff. She made supper for Megan's family so

that Megan and her husband could spend time together after work.

It was quite a while before the doctors and nurses learned Megan's mom's name. It was Debbie. Debbie and her second husband moved from an active retirement community in Arizona back to the winters of the Midwest to care for their daughter. Debbie was not really thought of as a mom who needed to be part of her child's care because Megan was an adult.

One day, the doctor asked to speak to Megan and her husband about medical decisions, so Debbie left the room. "Well, I guess they don't need me in there," she said. "They have things to talk about." Her eyes were shiny and her posture a little less erect as she walked to the cafeteria for coffee while the doctor talked to her daughter and son-in-law about important things.

Debbie is an attentive, loving mother who had raised her daughter and launched her into independence more than 10 years ago. Now, this adult child is unexpectedly seriously ill, and an essential support person is left out. Because the doctors and nurses didn't know to offer information, practical aid, or a listening ear to Debbie, she was left in the shadows.

An Important Social Change

Every generation or so, social changes that seem completely unrelated interact together and result in an entirely new way of looking at how we relate to one another. Sociologists call this radical change *role realignment*; in corporate circles it is called a *paradigm shift*; and Hollywood calls it *the perfect storm*. This kind of paradigm-shifting perfect storm is occurring in health care

and family life and is realigning the way we think about parents and grown children. This social change has three parts:

- Older adults are living longer.
- The incidence of serious chronic disease in middle-aged adults is increasing.
- Parents are continuing active involvement in their children's lives well beyond adolescence.

In this second decade of the 21st century, adults are living so much longer that insurance companies are revising actuarial tables. Nearly 50% of adults older than 60 years old have at least one living parent.

At the same time, the huge baby boomer population is being diagnosed with chronic diseases in record numbers. The Centers for Disease Control and Prevention estimate that one-third of middle-aged adults are living with chronic diseases, such as cardiovascular disease, diabetes, chronic lung diseases, and cancer. These are adults who had been healthy as children.

The oldest in society may be the healthier parents of seriously ill, middle-aged adults. It is probably fair to say that when we think about parents of adult children, the general expectation is that as the parent ages and becomes more infirm, the child will become the caregiver for the parent. When the adult child is ill, however, fewer rules of behavior are available to guide the parent. The place in the family for parents in the care of their now grown, independent, but very ill, child is not clear.

Even in health care, this family change was not noticed right away, and there was no sudden realization that the phenomenon was happening. It is hard to say exactly when healthcare

professionals began to notice that with increasing frequency, seriously ill adult patients had living parents. These parents were relatively healthy and seemed to help our patients and their families in many ways. They were present in the hospital and during outpatient treatments. Usually, they were quiet. When they asked questions, it was typically in a respectful and slightly hesitant way. When planning care for adult patients, healthcare providers usually label parents as “support systems” or “family resources” because parents helped the patients by shopping and caring for grandchildren and driving to clinic appointments. They were quiet helpers, not decision makers. They were in the shadows.

Over time, it became obvious. These important family members were not getting the help they needed. Surely adult children expected different things from their parents than minor children, but those expectations were not well known. Understanding of parental desire to assist their adult children was nearly absent. Some of these answers depended on the age and independence level of the child and the closeness of the relationship. Certainly, common sense and intuition implied that the parent-child bond remained strong even when the child was grown.

Not much is known about how parents could best relate to children as mature adults rather than as dependent immature children. Books and Web sites that address parent and adult child relationships largely send conflicting messages: *Let adult children plan their own lives. If you help them too much, they will resent you. Stand by, however, because your adult children often call upon you for assistance. Be friendly, but not their friend.* Adult children and parents were left to follow unspecified guidelines.

Even less is known about the experience of navigating the healthcare system with an adult child who had established independence from parents and was now very sick. What was known led to more questions than answers. How were parents supposed to behave with their child's spouse? Given strict laws governing the privacy of health information, how much and what kind of information should parents expect? How much help was enough? What kind of help was needed and most appreciated? Did parent age matter? Did the child's age matter?

A few parents were forthcoming. Casual comments ranged from resigned to resentful to guilty to gratitude for the ability to help: "I thought this was *my* time. I didn't expect to come out of retirement to take care of my kids again." "What can you do? He's my son, after all." "Do you think I caused the breast cancer? It does run in my side of the family." "Thank goodness I am healthy enough to help out. I would do anything for her and her family."

Historical Perspective on Parenting

Because professional experts were few, it became obvious that the real experts needed to be consulted: the parents of seriously ill adult children. But first, a historical perspective on parenting and health care was needed. The past three generations of parents, more than generations before them, anticipate continued close involvement with adult children. Understanding what influenced those parents when their children were young was essential to understanding why continued attachment was valued, even expected. Interest in parenting started in earnest right after World War II.

Drs. Benjamin Spock and Jonas Salk greatly influenced the parenting movement. Dr. Spock was the first popular expert on what we have come to call good parenting. Dr. Salk's research successes provided evidence that we could believe in the near infallibility of modern medicine to keep children alive and healthy to adulthood.

Dr. Spock, the pediatrician who came on the national scene right after World War II, delivered a most controversial message: Children are not just little adults. They are unique individuals.

In his book *Baby and Child Care* (1946), Dr. Spock told parents that just feeding, clothing, and telling children to follow the rules was not good enough. Children need love. Don't worry about spoiling your children. Raising children was an important job, maybe the most important job ever, Dr. Spock told parents.

America was ready to listen. World War II was over and the economy was on the upswing. Prosperity, along with respect for the job needs of returning veterans, made it possible for moms to stay home and care for the kids while dads worked. There was a boom in births. Raising baby boomer children took on importance because it was one outcome that stay-at-home moms could point to as evidence of their worth.

Dr. Spock poured a solid foundation, but he was just the beginning. Children and parents began to be studied in earnest. Baby boomer children were arguably the first generation who were openly loved and cherished—and studied—by society. Names such as Thomas Gordon (2011a, 2011b), Don Dinkmeyer Sr., Gary McKay, and Don Dinkmeyer Jr. (2007), and James Dobson (1997–2012) became widely recognized. These

psychologists, clergy, and social scientists gave parents skills to effectively communicate with and discipline children. They each carried a similar message: Being a parent takes new knowledge. Being a parent requires skills and purposeful action. You are not just born with the ability to be a good parent. You have to be purposeful about it. You need to understand growth and development. Children need to be pruned, not yanked, supported and encouraged, not punished and ridiculed.

In fact, being a parent required a new word: “Parenting” became an active verb. Parenting has come to mean thoughtfully considering family values and the developmental stage of each child to foster self-esteem, intellectual curiosity, and regard for others. Because parenting is a job, parents must need skills. Parents began taking parenting classes with acronyms such as PET (Parent Effectiveness Training) (Gordon, 2011a), FET (Family Effectiveness Training) (Gordon, 2011b), and STEP (Systematic Training for Effective Parenting) (Dinkmeyer et al., 2007). The trend continues. Women’s magazines almost always have at least one article on effective parenting. Churches and community centers offer classes on parent-child communication, disciplining with love, natural and logical consequences, Mommy and Me, parenting teenagers, parenting by the Bible, and so much more. Ever since Dr. Spock gave parents of baby boomers the charge to raise children well, parents have been asking: How can I tell if I’m a good parent? What should I do to nurture my child? What is good-enough discipline? Is spanking OK? Would my child be OK if I bottle fed him? Would my child be ruined if I went back to work? Should I communicate with my child as though I am in charge or as though our home is a democracy, or is befriending my child

the best approach? Intense discussions about parent-child relationships occur in popular magazines and professional journals, at parent-teacher organization meetings and backyard barbecues. Parenting Web sites and blogs were created to give parents a forum to discuss ideas and worries about raising young children.

Over the past 65 years, the message has only become clearer and more refined: a young child becomes a successful adult by developing self-confidence and positive social relationships. The foundation of all child development rests on genetics and the first relationship of all, the child and the parent. Guilt has become a part of every parent's life.

Parents race toward the prize: graduation and independence, and hopefully, a good job and marriage, and pray God, healthy grandchildren. The children were raised. The job is done.

And then, the advice . . . almost . . . completely . . . stops.

Parents of adult children don't have many guideposts on the journey to a "grown-up" relationship with their independent children. The most consistent advice for parents is a bit like this: Don't give advice, and don't appear too needy and hope the kids keep coming around. This kind of parenting advice does not give much guidance when grown children become very ill and dependent.

Parents invest a great deal of themselves into raising children. Even when children have been independent for many years, the bond continues. In the words of Toni Morrison (2006), "Grown don't mean nothing to a mother. A child is a child. They get bigger, older, but grown? What's that supposed to mean? In my heart, it don't mean a thing" (p. 57).

Medical Miracles and Parenting

Parents have the luxury to focus on the emotional side of parenting because of medical pioneers like Dr. Salk. Jonas Salk, MD, was a physician and medical researcher who developed the polio vaccine. Although the polio vaccine was not the first vaccine, it was developed in the 1950s when summertime was a time of anxiety and fear for parents of baby boomers. Polio, or *poliomyelitis*, is a crippling and life-threatening disease that infected children most often in the summer. This highly contagious disease attacks the central nervous system and is spread by eating or drinking the polio virus. Epidemics typically occur in warmer climates and when groups of people are active. The combination of spirited outdoor activity with friends coupled with summer temperatures made children susceptible to infection (Nichols, 2012). Polio affected many thousands of children every year. Whole communities isolated children in the summer. Parents felt powerless and frightened. The polio vaccine lifted that fear. Medical science came through (Kluger, 2004).

Dr. Salk was certainly not the only medical scientist working on amazing treatments to control and prevent disease. He is only one of the most famous because most baby boomers remember standing in long lines at schools or churches to get a shot or a sugar cube to prevent a paralyzing disease.

Amazing medical breakthroughs have occurred since the second half of the 20th century. Babies who would have died even a generation ago are alive and well today because of advances in newborn care. Today, some cancers are curable, and most are treatable and result in chronic illness rather than an automatic death sentence. Diabetes is controllable. Drugs that

keep cholesterol levels low, blood pressure down, and damaged lungs functioning are commonplace. Medical science can hold at bay the results of our poor lifestyles. DNA was discovered in the 1950s. Genes were mapped, and then amazingly the exact locations of some disease-producing chromosomes were found on genes. Some diseases can be diagnosed before birth and treated immediately after birth. Some conditions can even be treated before birth with prenatal surgery.

Whether ill or healthy, people have been encouraged to learn about their health. The popular phrase is “advocate for yourself.” Ask questions. Expect to participate in decisions with your healthcare provider. Check the Internet. Ask your healthcare providers for written information about everything prescribed or diagnosed. Get a second opinion. Read your chart. *You are in charge of your health.*

With all that medical success and all those self-affirming mantras, it is understandable that we may have the illusion that all diseases can be cured, or at least treated for a very long time. If a disease does not respond, the problem must be the doctor’s fault or the person is not fighting the disease hard enough. In the words of Fr. Joseph Cardone, a Roman Catholic priest (personal communication, June 16, 2010), “some of us even think medicine has made death optional.”

Drs. Spock and Salk have taught us two important lessons. First, willingly or reluctantly, once a parent, always a parent. Second, parents of children of every age look to the healthcare system to help make things better. Parents of young children expect to be included in medical decision making when their children are ill. Parents of adult children want to be included, but don’t know what to do or how to behave.

Debbie's Story

Debbie's need to parent her seriously ill adult child was not well understood by her daughter or the healthcare team. When she asked Megan and her husband if she could listen in when they talked to the doctors, she was pleased with their response. Although her role continues to be supportive, Debbie now feels as though she is an important part of her daughter's medical treatment plan.

Conclusion

In the Shadows: How to Help Your Seriously Ill Adult Child is a book of stories, evidence, and advice that is the result of hours of interviews with parents, their ill adult children, and professionals. The parents' stories are accounts of real people told as faithfully as possible but with identifying details and names changed. When asked, parents were eager to talk and tell their story. They would explain what their experience was like and what they wish healthcare providers could have done to help them. They gave advice for friends and other family members. Some lessons were hard to learn. These parents asked that their stories be shared in the hope that their perspectives will help others find some guidance to support their ill adult child and themselves.

The insights and resources are described in 10 chapters. Chapter topics include parenting adult children, your other important relationships, emotional responses to having an ill child, providing physical care to your ill child, financial con-

cerns in serious illness, caring for yourself, communication challenges when serious illness occurs, how spirituality may help you cope, navigating the healthcare system, and coping with your child's prognosis.

Having an ill child of any age is difficult. May these stories and advice shed light for you and your family. You are not alone in this journey. We wish to help you move from the shadows as you and your child live your own story.

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