

CARING



June 2001
Vol. XX, No. 6

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Welcome to Our Home

An Open Letter to Home Care Professionals

by Albert Freedman, PhD

Dear Home Care Professional,

Welcome to our home.

Since you are new to the team of professionals who care for our son, I'd like to share some background with you as a way to begin our journey together.

Six years ago when my wife, Anne, and I decided to become parents, we didn't plan to meet you. Back then, we didn't know anything about pulse oximeters, wheelchairs, bi-pap (two-way positive airway pressure) machines, feeding tubes, nebulizers, or standing frames. We didn't plan for the parade of nurses, social workers, occupational and physical therapists, assistive technology specialists, medical supply personnel, teachers, and case managers who come and go. We didn't anticipate the need for five different doctors to monitor our son's progress at the local children's hospital. And we didn't plan for our child to spend 56 nights in the Intensive Care Unit before he reached his third birthday.

Most of all, when we decided to become parents, we didn't anticipate that very bad day when a doctor told us our six-month-old baby had a year to live.

So I hope you don't take it personally when I say I have mixed feelings about your presence in our lives. Frankly, I wish we didn't need you. I wish our son were

going to kindergarten with all the other kids his age, scraping his knees, running around outdoors without his coat on, and spilling Elmer's Glue on his lap. I wish I were spending my weekends watching my son play soccer.

But Jack isn't going to kindergarten, and he isn't playing soccer. He can't sit up, walk, or talk very clearly. He can't move his arms or legs. He can't dress or feed himself. He still uses diapers. He can't eat solid foods. He needs constant supervision and attention. He's medically fragile. His care is physically and emotionally demanding.

I wish we didn't need you, but we do need you.

We need your positive attitude and your confidence. We need your sensitivity and patience. We need your knowledge, experience, and skills. And we need you to help us have hope, for our son and our family.

*

When you begin your work with our son, please carry yourself with confidence. You've been trained to take care of medically fragile children and we haven't. Jack's care requires remembering little things about his needs: what's safe to feed him, how to lift him into his wheelchair, when to remove his secretions, how to set up Jack's arm supports so he can use his computer, which way to turn his head when he lays on his stomach, how often to give him a syringe of formula through his feeding tube. Although

none of this is rocket science, the sheer number of details can feel overwhelming to a newcomer. But if you feel overwhelmed, try not to show it. Act confident. Take initiative. Have a positive attitude. Watch us as we demonstrate how Jack's equipment works. Ask us questions. Write things down if it helps you. Enjoy yourself when you're working. But above all, carry yourself with confidence. Jack will feel safe if you feel safe.

*

When you begin your work with our son, please be patient with us. We may insist about certain aspects of Jack's care that don't make perfect sense to you. It may be awhile before we leave you alone with our son even though you're perfectly capable of taking care of him. You may wonder why we ask you about your own health every time you sneeze or cough in our house. We realize we worry about Jack just about all the time. Please understand that we simply can't help it. From the moment the doctor sat us down and told us our baby had an incurable, untreatable disease, things were never quite the same again. We really are doing the best we can.

*

When you begin your work with our son, please be sensitive to our family's need for privacy one minute and our need for your active involvement the next minute. (As a wise home care administrator I know tells each of her new clients, "The good news is...you'll now be getting nursing help in your home. The bad news is...you'll now be getting nursing help in your home.") It's a skill to know when to be involved and when to act invisible. Do your best to fade into the woodwork when Anne or I need to parent our son. But get right in there with Jack's physical therapist if she needs your help. Pretend you're not in the room when I answer the phone and it's a client emergency. But offer to pick up the phone if it's ringing and Anne has her hands full with our baby. If you're not sure which approach to take in a given situation, feel free to ask.



We'll try to be sensitive to the needs of your family, too. Let us know if you need flexibility with your work schedule because your mother is visiting from out of town or you'd like to attend your daughter's school play. It feels good to us to help someone else's family once in a while.

We'll help you out whenever we can.

*

When you begin your work with our son, please take the time to get to know him as a person.

Yes, you're here because of all the things Jack can't do by himself. But there's a lot he can do, too. You'll be surprised the first time you see Jack drive around independently in his power wheelchair. Try to keep up with Jack as he clicks his way through a tricky challenge on the computer. Feel free to join him in the swimming pool while he works hard in the water with his therapist. Listen to him tell jokes using his communication device. Enjoy Jack enjoying the company of his baby sister. Soak up his positive attitude, determination, and his smile. We think he's quite a kid. We hope you will, too. And when you show a genuine interest in Jack, he will fall in love with you very quickly.

*

When you begin your work with our son, please teach us what you know about caring for him.

After Jack's diagnosis, one of the first things we heard from medical professionals was, "You will soon be the experts on Spinal Muscular Atrophy (SMA) and caring for Jack." But I didn't want to believe our baby had such a terrible disease, much less become an expert on it. And

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more importantly, if Jack really did have SMA and would die because he couldn't breathe, how in the world could we become experts on how to help him? After all, isn't that what doctors and nurses are for?

Our son is intelligent and sensitive; he observes all of our words, actions, and signals. Jack needs us to view his disability and his future with a sense of hope, whether life feels manageable at the time or not.

Gradually, we did become experts on SMA because Jack is our son and we had to do whatever we could to help him. But for more than five years now, I feel relieved every time we meet a professional who knows more about caring for a medically-fragile child than we know, or at the very least can teach us something new. As you begin working with our son, tell us what you know, tell us what you've learned, tell us what you've seen. We take care of only one medically fragile child. You've taken care of many more than one. You can provide us with some perspective. You can give us a reality check when we need one. You can help us take care of Jack when he's sick. We need your expertise. That's why you're here. Please don't hold back.

*

Finally, and perhaps most importantly, when you begin your work with our son, please help us to have hope.

When we first learned Jack was affected by Spinal Muscular Atrophy, hope was a scarce commodity in our home. We didn't hear much from the doctors about living with Jack from day to day—they didn't tell us about the good days we would have together as a family. Looking back, I now realize it was Jack's job to teach us these important lessons. After all, doctors at children's hos-

pitals don't spend a lot of time with kids when they are well. Parents do that.

Our son is intelligent and sensitive; he observes all of our words, actions, and signals. Jack needs us to view his disability and his future with a sense of hope, whether life feels manageable at the time or not. Three years ago, when Jack's bout with respiratory syncytial virus (RSV) led to intubation and a three-week hospitalization, it was very hard for me to be positive and hopeful. But as I looked at my son lying in the intensive care unit, kept alive by a ventilator, his eyes wide open wondering what was happening to him, I believed it was important for Jack to see me smiling and to hear me telling stories as usual, giving him the message that I was hopeful and confident of his ability to recover from his illness.

Somehow, Jack did bounce back from that harrowing illness. And ten days later, after he had been successfully extubated and we were preparing to go home, the head physician in the Intensive Care Unit came by to wish us well. He talked about Jack's remarkable recovery, and he was obviously pleased to be a part of it. But the doctor's focus was not on the treatment plan, the efforts of the hospital staff, or his own good work. He attributed Jack's recovery to the patient himself.

"Jack's a fighter," the doctor told us, quite matter-of-factly.

Indeed, Jack is a fighter. All of the children you care for are fighters. But our children cannot fight without hope, and it is up to us—parents and professionals together—to keep hope alive.

We appreciate everything you do. Welcome to our home.

Sincerely,

The Freedmans



About the Author: Albert Freedman, PhD is a psychologist who works with children, adolescents, and families in private practice and at Westtown School in Westtown, Pennsylvania. He and his wife, Anne, are the parents of two children, Jack (1995) and Cara (2000). Dr. Freedman provides consultation and inservice training to professionals in health care and educational settings, and he is a frequent presenter at regional and national conferences on the topic of caring for children with special needs. His essay, "The Future is Now," is included in a newly published book, *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities* (Kensington Publishers, 2001). Dr. Freedman can be contacted via email at freedman@fsma.org.

