

# What It Means To Care

By Albert Freedman

## Dear Home Health Care Professional,

Six years ago, in an open letter published in *CARING* magazine, I welcomed you to our home (Freedman, 2001). I told you about our six-year-old son, Jack, who at six months of age, was diagnosed with an incurable neuromuscular disease called Spinal Muscular Atrophy (SMA), and given one year to live. I told you about the many nights we spent in the intensive care unit at our local children's hospital, and the medical equipment our son needs on a daily basis: the pulse oximeter, feeding tube, cough-assist machine, standing frame, wheelchair, and Bipap ventilator. In my letter, I asked you to approach your work with our son with confidence and compassion. I asked you to share your knowledge by teaching us what you know. I asked for your patience and understanding because we worry about Jack all the time. Most importantly, I asked

you to help us have hope for our son and our family. When I wrote "Welcome to Our Home" late one night, I didn't think anyone would actually read my letter. I was surprised when my words were published in *CARING* magazine, and I was even more surprised to receive email messages from across the country in response to my story. Nurses, physicians, ministers, home care administrators, social workers, policy-makers, and parents and relatives of other pediatric patients provided words of encouragement and appreciation. I'm pleased to know "Welcome to Our Home" has been used to orient, train, teach, and recognize home health care professionals in so many places. Six years later, the editors of *CARING* magazine asked me to write to you again, so I suppose I should say ... **Welcome back to our home.**



The Freedman Family shown here left to right, Anne, Jack, Cara, and Al.

Nurse Bridget with Jack in his standing frame.



Nurse Lorie, Jack, and Cara on Halloween.



Jack, Nurse Ellen (top right), and the staff of the PA Vent Camp

Our son, Jack, is not a little boy any longer. He's twelve years old, and on the cusp of becoming a young man. Jack attended school almost every day of fifth grade, and he is excited about beginning middle school in the fall. He's able to operate his power wheelchair and his computer independently. He loves swimming, going to the movies, and traveling to the beach and to a special camp in the summer. Most importantly, Jack is happy. He feels good about himself, and approaches every day with confidence and a positive attitude.

The past six years have not been easy. Our son continues to face many medical challenges. Five years ago, Jack underwent spinal fusion surgery to correct severe scoliosis. Four years ago, he was fitted for a new motorized wheelchair with sensitive fiber optic switches because he has almost no movement in his arms and fingers. The wheelchair is larger because Jack has grown, so we needed to purchase a conversion van with a wheelchair lift.

Three years ago, we moved to a new home and made major modifications to accommodate Jack's wheelchair and other medical equipment. Our son's bedroom now includes a specialized hospital bed, a gurney, a ceiling track lift, a potty chair, and an emergency oxygen supply. A large generator outside our home provides electricity when power outages occur. Over the years, I've lost track of the number of nights Jack has spent in the pediatric intensive care unit. We spent a week in the hospital last December as our son fought through a severe respiratory illness.

Every day seems to present a new trial as we work to keep up with Jack's special needs. But despite the many challenges we face as a family, we feel fortunate to have every single day with our son. Twelve years after being given only one year to live, Jack is very much alive. Against all odds, he has somehow overcome one obstacle after another with determination, dignity, and a very positive spirit. We are very proud of our son.

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How have my wife, Anne, and I coped over these twelve years? How have we faced the complicated and unique challenge of caring for a severely disabled, medi-

cally fragile child? Being Jack's parents is not easy, and there are times when we feel overwhelmed, discouraged, exhausted, and alone. Families like ours can not bear the burden of our parenting responsibilities entirely on our own. When other people support us, we're stronger as a family, and our lives feel more manageable. Our family and friends do the best they can to help us, and personal support is critically important. But given Jack's medical fragility and the demands of his day-to-day care, we need the help of professionals who have the knowledge, experience, and skills to help us take care of our son.

As I reflect back on our twelve years with Jack, I've concluded that there is one simple but critical ingredient that sets some professionals apart from others. There is one characteristic that determines whether we feel a professional can truly help us. It's hard to measure, and impossible to teach. It's expected of all health care professionals, but isn't always evident to patients and families. With it, relationships are immediately strengthened. Without it, building trust is next to impossible. What, exactly, is this necessary ingredient?

It's written across the cover of this very publication you're holding in your hands. *CARING*. Families like mine need the help of professionals who demonstrate what it means to care.

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Over the years, dozens of professionals have worked with Jack and our family: physicians; speech pathologists; physical and occupational therapists; special educators; pharmacists; respiratory therapists; social workers; medical supply vendors;

wheelchair, van conversion, and assistive technology specialists; and contractors for our home. Each of these professionals has played an important role in helping us with our son, and many have demonstrated what it means to care. We are indeed grateful for their help.

But every step of the way, one professional accompanies Jack wherever he goes. That's you, Jack's home care nurse. Because you spend so much time with our son, you have a unique relationship with Jack and our family. You're with Jack at school, and help him interact with peers and his teachers. You're with Jack and our family in our home, so you observe our good days and our bad, our strengths and our stressors. Of all the professionals we work with, you have the ability to make the greatest impact on our son and family on a daily basis, every month of the year. As pediatric home care nurses, each of you has shown Jack what it means to care in your own unique way. Although all of you follow the same treatment plan, each of you brings something distinctive and special when you join us in our home.

You demonstrate what it means to care every time you talk with Jack as you transfer him to and from his wheelchair, feed him, dress him, give him his medications through his feeding tube, and help him with his breathing treatments. You demonstrate what it means to care every time you help Jack communicate with his classmates at school, every time you adjust the switches on Jack's wheelchair so he can drive independently, and every time you read him a story. Jack relies on you, respects you, and cares about you. Jack cares about you because he knows you care about him.

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I believe most people choose to work in health care because they care about other people and want to help. Why, then, does there appear to be a shortage of truly caring health care professionals?

Over the years, I've come to realize that professionals are best able to demonstrate what it means to care when they feel supported and cared for in their work. As a home care nurse, you play a unique role working in the homes of patients and their families.

You, too, need support to do your work with care. You need and deserve adequate orientation, training, and supervision. You need ongoing communication with your agency's support staff, and you need to feel part of a team. You need to know your agency will help you when you need help with a child. You need to be fairly compensated for your time and work. You will be better able to care for your patients when your home health care agency demonstrates that it cares about you.

In our society's current health care environment, your agency may be hard pressed to provide you what you need and deserve. When Medicaid funding and programs for disabled citizens are reduced or eliminated, nurses like you can not be adequately supported and compensated. When insurance companies freeze reimbursement rates for years at a time, health care organizations find themselves unable to attract and retain professionals to care for our family members. Our society as a whole needs to demonstrate what it means to care if we would like our health care professionals to follow suit.

As the population ages and as more children like Jack beat the odds, home care services will become increasingly important. Will our federal and state leaders demonstrate what it



**Nurse Sharon with Jack, operating the ceiling track lift.**

means to care by supporting organizations and professionals that support families like ours? Will health care policymakers demonstrate what it means to care by offering our most vulnerable citizens access to high quality home care services?

Certainly, our country's health care system leaves much to be desired, and the wheels of change move very slowly. Meanwhile, families like ours live our lives one day at a time, grateful for

the support of nurses and aides who, working against the odds, find it in their hearts to care. To you, home care professionals everywhere, please know how much your work is appreciated. We did not choose to have a medically fragile, disabled child. But you did choose to become home care professionals. Families like ours are very fortunate and grateful that you made that choice.

## Thank you ...

**Bridget**, for jumping in with both feet when Jack became ill the first week you began working in our home. You cared for our son with confidence, compassion, and skill before and after Jack's hospitalization, and through the holidays. We appreciate your ongoing efforts to help Jack with his school work and his social skills beyond the scope of the care plan. We feel so fortunate to have you on Jack's team.

**Lorie**, for being part of Jack's life for over five years. Jack considers you a part of our family. When you encouraged us to take Jack outside for winter sledding, you helped us discover a whole new way to enjoy the snow together. Visiting our home in your Halloween costume each year, whether or not it's your day to work with Jack, tells us how much you care about our children.

**Amy**, for your kindness to Jack and our family. When I called home during a lightning storm, I heard the concern in Anne's voice. Jack was fighting a cold, and there was a chance our house could lose power. At the time, the portable generator was our only back up. You offered to stay past the end of your shift until I arrived home. You gave Anne peace of mind. She would not be faced with a choice between staying with Jack or going outside into a storm to crank up the generator.

**Sharon**, for your soft-spoken, positive approach with Jack, and for your kindnesses to our daughter, Cara, too. It's not easy being Jack's younger sister, and we appreciate your friendship to both of our children. We also appreciate your encouragement to enroll Jack at summer camp. You were right. He was ready to go!

**Patrice**, for your commitment to our son for the four years you worked in our home and as a nursing supervisor. Your professionalism, positive attitude, and willingness to take initiative had a direct and positive impact on Jack and our family. While we were sad about your decision to seek a new professional opportunity, we know you are taking good care of other children. Your generous offer to stay connected with our agency so you can spend an occasional evening shift with Jack speaks volumes about how much you care about our son.

**Ellen**, for volunteering your time to care for Jack for four days at the Pennsylvania Vent Camp, an overnight camp for medically fragile children. From the moment Jack awakened early each morning until he closed his eyes each night, he knew you would be with him at every activity. Camp has been a life-changing experience for Jack and our family, and we are very grateful. As a nurse, you exemplify what it means to truly care.

*To each of you, we offer our heartfelt gratitude and a warm welcome back to our home. Jack is very fortunate to have you in his life. Each day, you continue to teach me, and my family, what it means to care.*

**References:** Freedman, A. M. (2001). Welcome to Our Home: An Open Letter to Home Care Professionals. *CARING*, 20, 8-11.



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