

HOME CARE & SEPTEMBER 11: CONNECTING WITH OUR CLIENTS IN TIMES OF UNCERTAINTY

*An Interview with
Mark Baiada & Albert Freedman*

by Carol A. Trueman and James E. Murray

In keeping with the theme of this year's National Association for Home Care & Hospice 22nd Annual Meeting and Third World Congress on Home Care and Hospice, "Home Care & Hospice: The Heart & Soul of Health Care in America & Around the World," the authors recently conducted an interview with Albert Freedman, PhD, psychologist and father of a medically-fragile child; and Mark Baiada, founder and president of Bayada Nurses. These two gentlemen discussed the parallel between the impact of their personal experiences and those of the nation following the attacks on the Twin Towers and the Pentagon. From the great personal pain, angst, and fear wrought out of their own family experiences, Freedman and Baiada relate how families caring for a medically-fragile loved one experience their own "September 11" when the health of a family member changes abruptly, and they emphasize the importance of a genuine connection between home care professionals and emotionally vulnerable families .

James E. Murray (JEM): The tragedy of 9/11 filled the country with fear and uncertainty, and still continues to traumatize people. Just as significant, and perhaps paralyzing more so, is the crisis that occurs when a life-threatening situation touches a family. Your family's personal crisis in dealing with your son, Jack's, catastrophic illness, Al, was a reverberation for you when 9/11 occurred. Can you comment on that?

Albert Freedman (AF): Yes, for six months, my wife and I had a healthy baby and were going along with our lives in a reasonably predictable way, or at least as predictable as life can be with a newborn. Things were going just as they



Mark Baiada (left) and Al Freedman

were supposed to go—our baby was growing and we were tired but very happy. Then one day, our whole sense of control and security crashed on top of us when a doctor told us our six-month-old baby, Jack, had spinal muscular atrophy (SMA), an incurable neuromuscular disease. We were told Jack would live only for a year and that each time we conceived a child the odds of this disease were one-in-four. So, in a matter of minutes, we were, as a family, traumatized. Our sense of safety and our understanding of how the world worked was disrupted. We felt fearful and vulnerable. In the beginning, we didn't believe this could be happening to us. It was such horrible and sudden news it just didn't feel real. So that was our "9/11"—November 7, 1995. For the country, 9/11 was symbolic in that the nation's sense of order, safety, control, and routine was horribly disrupted. Everyone's idea of their safety living in the United States changed

in a very traumatic way. People watched these horrific events on television and asked themselves, “Is this real? Can this really be happening to us?”

JEM: And that would be the personal perspective and reflection. Mark, you have had a personal trauma as well. Can you comment on this, also?

Mark Baiada (MB): I’ve had a similar experience as a parent. My daughter, who was just about five years old at the time, went for a routine physical. At the end of the day we were told that she had leukemia. When the doctor told us the chances were 50/50 our daughter’s disease was fatal, we were numb. Suddenly, our world turned completely upside down—it was our 9/11. Thank God the story ended happily, as she recovered completely.

JEM: Mark, you now experience major crises daily in your professional life. Working within the area of home care and hospice, how do you see your agency and your staff responding to the families you serve in the type of crisis you’ve just described?

MB: We serve the patients and their families as a unit. We visualize the families whom we serve as more than clients, especially in pediatrics. When they initially come to us for help, they don’t want us, they need us. This is a difficult time for a family and also presents a challenge for us as home care professionals. We do our best to respond to the family’s crisis, and our staff’s goal is to make life as good as it can be for a family given the difficult circumstances. Sometimes the feelings of family members are hidden to the staff in their daily work of providing the service, and sometimes the feelings of family members are out in the open but hard to respond to. Every family responds to a crisis differently, which is understandable, but sometimes the range of reactions can be confusing to a professional entering a crisis situation. Al has been helping us by reminding every nurse, every aide, and every office member that the initial crisis which leads to a family’s need for home care is a “September 11” for that family, and our job is to be as supportive and skilled as we can be.

JEM: Al, Mark just said something that struck a chord. Can you, as a psychologist, develop it further? Mark said, “They don’t want us, they need us.”

AF: That’s right. It’s important to remember in home care that no one chooses to become a patient or the family member of a patient. You’re suddenly in a club you didn’t choose to join; it’s a club that most people can’t imagine being part of. It takes time to accept that you have a life that’s different and that your needs are different. And with that realization usually comes a good bit of compromise and adaptation. Early on, it is very common for a family’s shock and trauma to be visible to professionals when they enter a home to care for a new patient. Yes, Mark’s nurses are people we need, but it took a lot of time for us to genuinely welcome them into our home. Initially, my wife and I didn’t know how to make sense of a nurse being with us at home.

We didn’t know how to share Jack’s care with our nurses. We didn’t know what to expect, we didn’t know what to do, and we didn’t know what was right or wrong. We needed help from the people in Mark’s company who supervise and educate to teach us exactly what the nurses were in our home to do. There’s a lot of “give and take” involved—it’s complicated to share your home and your family and your day-to-day lives with people you don’t know. For us, it has now been eight years since our family’s “September 11” when Jack was diagnosed with SMA. Over time, I think there’s a kind of equation that each family develops for itself. After a while, families basically weigh the pluses and the minuses of having a professional in their homes versus not having one. The job of the home care professional is to convince the family—by providing supportive, reliable, and skilled care to the patient—that the advantages of having the nurse or aide in the home outweigh the disadvantages.

JEM: I once heard the father of a terminally ill pediatric client make a comment about having nurses constantly in his home over a period of eight years, because the child was on a ventilator. When the child was eventually admitted to the hospital, the father said, “Let me put it to you this way; for the first time in eight years I can walk around my home in just my underwear.”

Mark, you’re the administrator and owner of a very large home health care organization headquartered in New Jersey and have expanded into a wide area of the country. Bayada Nurses has become a large company. How many offices do you have out there now?

MB: We have 100 offices located in 15 states.

JEM: And you have developed sensitivity, it seems, toward the emotional issues, the psychological concerns of the patients and families. What have you seen within your agency, for instance, as your staff members try to prepare themselves? Do you have any programs that prepare staff to



Freedman with his son, Jack (in chair), daughter Cara, and wife Anne.

go into “9/11” situations that are present within the personal lives of families?

MB: Well, the whole culture of our company has always been about helping people—and we’re always trying to improve what we do. We provide our field staff with workshops, in-service training, and supervision. Of course, many of these sessions are focused on needed medical procedures, but we are paying increasing attention to the emotional needs of our clients and families. That’s why we’re working closely with Al. The relationship between our professionals and our clients has to be one of connectivity. Al is helping us learn what families like his want and need from their home care providers. We connect with Al and Anne (his wife) as examples of parents doing the best they can under extraordinarily challenging circumstances, and we connect with their son, Jack, as an example of a young client with special needs who is doing the best he can, too. It’s our job to find out what their needs are because taking care of a medically fragile child is complicated, and they need help doing it. We’re looking to get to know them because they have their routines in their homes, and we want to help maintain the routines they have rather than impose ours on them. They should have direction and control—it’s their home, for God’s sake. And remembering that each family’s starting point with us is their own version of “9/11,” as Al points out, it’s crucial that we help the family experience a sense of control whenever we can.

JEM: Why is that so important? Isn’t your job to go in there and provide professional services?

MB: Well, we do, but the timing, the pace, and all of that should be adjusted, and it should be adjusted, I feel, not to necessarily have it at our pace, but at the family’s pace and patterns. It must be more service-oriented because then hav-

ing someone in their home is easier for the family to handle. They feel their home is their castle, and it usually takes a little bit of time to work out the relationship so our work can be done safely and effectively, but also as non-intrusively and supportively as possible. It’s a constant process of connecting, adapting, and supporting.

JEM: Why is the psychology of that so crucial in the delivery of home care? I’d like to hear both of you address that.

MB: Well, speaking from Al’s point of view and the view of all clients, do you want someone in your home who really doesn’t care, doesn’t understand, and doesn’t try to support you to be in charge of your own life? Or to the other extreme, caregivers can be a little insensitive, too task oriented, and a little bossy. Sometimes families put up with an overbearing style because they know that the professional is competent. But the relationships are not quite smooth yet. The word Al and I use to describe when the relationships are working well is “connection.”

JEM: Can you explain that connection, Al?

AF: Yes. The nurses my wife, Anne, and I really want to have in our home caring for Jack, the nurses who we especially value, are the nurses who go beyond the procedural and the scientific aspects of the job. They take a genuine interest in our son and our family. These providers feel their work is meaningful; they come in the door feeling like they’re doing something meaningful for themselves as well. They enter our home with confidence; they come in with energy; they come in with hope. And all of these qualities are then transmitted to us in a way that allows us to be stronger as parents. Families, especially early on, sorely need those qualities. In many cases, the nurses and aides are very important role models for families struggling to adjust to a drastic change in their lives. Living with a medically fragile family member is challenging for everyone. But when a provider comes into the home behaving as though she has a meaningful job, wants to do it well, and cares about the person who’s the patient, the family is much more likely to feel supported and experience a genuine connection.

JEM: Mark, do you believe that kind of an attitude and mindset is created within your employees, and is contributing to the success of your organization?

MB: Yes, and our company is now actively working on a project called “The Bayada Way” to remind ourselves of the importance of these attitudes. The purpose of the project is to clarify and articulate our philosophy, mission, and core values. We want our people to repeatedly see and hear what’s really important to us as an organization even before they join us so they know what they’re getting into. We are, of course, hoping good, competent people will self-select based on what they hear us say about what we do. We’re always looking for staff who relate to our values so when they do come on board, they’re open to the Bayada Way of doing things.



Baiada and daughter Jan.

Carol A. Trueman (CAT): How do you formally train your staff and your nurses to be compassionate and caring, to elicit these qualities from them in the course of tending to patients and their families in kind, connected, and loving ways?

MB: We provide in-service days and continuing education opportunities for our field staff, and all of our nurses and aides receive direct supervision. We find the socialization that comes with the supervisory and educational processes very helpful; in general, if you're part of a group, you will tend to move toward the group's norms. Finding caring and compassionate professionals also has to do with how we advertise and how we interview, as well as the quality of our orientation and training programs.

CAT: I can imagine anyone who would go into this field is an individual who has, innately, a great deal of compassion. People don't usually go into this type profession—which can be rather depressing and laborious at times—unless they really care about people. But at the same time, these individuals must also have to have a great deal of inner strength so that they can provide the type of hands-on caring approach that Al is talking about.

MB: By and large, they are caring people. That's why they chose nursing. On the other hand, because a lot of their work involves very specific and prescribed procedures, they can be very task-oriented people. And many of our nurses come to us from hospitals, where because of the pace of the work and the need to care for multiple patients, there is less time to really connect with patients. So, for traditionally trained nurses, there is often an adjustment period as a nurse begins working in a home.

CAT: Al, you have worked with Mark to develop in-service programs for the Bayada organization. How do these types of sessions help home care professionals to be more effective in their roles?

AF: Yes, I have provided in-service training sessions, and I have conducted focus groups with over 200 Bayada employees at all levels of the organization. These sessions have been part of "The Bayada Way" project Mark mentioned, with the goal of refocusing the staff to the meaning and purpose of their work. When home care professionals are asked to reflect on questions such as, "What is at the heart of the work you do as home care professionals?" and "What makes your work meaningful to you?" the responses reveal a great deal about the core values and beliefs of the individuals and of the organization. Home care professionals are, indeed, very caring and committed people. The exercise of reflecting on the meaning and purpose of their work is a soul-searching process, I believe, that parallels the experience of many of us in the country after September 11 who asked ourselves,

"What's really important in my life?" My sense is that home care professionals who are provided the opportunity to reflect deeply on the meaning of their work will be better prepared to connect with and support the vulnerable clients and families they serve, most of whom, to emphasize the point, have struggled with their own version of "September 11" when their lives were turned upside down.

JEM: Are you both saying, then, that the most important part of health care delivery is the emotional and psychological?

AF: I believe the key to providing quality health care involves both art and science. The question is similar to asking which leg of a chair is the most important. It's hard to say, isn't it? If one of the legs of the chair is not sturdy, you will not want to sit there because it wouldn't feel safe. What I am saying is that patients and family members feel safest when both the medical procedures and the emotional support are provided.

MB: My feeling is that medicine in this country has been driven to a large extent by economics, technology, and liability concerns. Because those needs have dominated the medical world and have dominated the training of professionals and the provision of services, the emotional needs of the patient and the family are often inadequately addressed.

JEM: So people want more from their health care providers.

AF: Sure, people want more, especially in their homes. In your home, a strictly procedural approach doesn't make sense because your home is your home, and first and foremost in every home is a family and relationships and a lot of give-and-take. Certainly, there need to be procedures and there needs to be record keeping in home care, but there also needs to be conversation and a connection and a working relationship. In a home, a professional has the ability to focus on the needs of the patient well beyond the chart. Home care professionals have a unique window into the entire lives of their patients. There's a lot to see if you look through that window.

JEM: I'm getting the sense that from the perspective of the patient, it is, 'Yes, I need a skilled individual who is able to provide the medical services first and foremost. But after that I'm also looking for somebody who can understand my fears, and help to calm those fears in me, and help me to overcome some of the challenges. And, if I can find that with the home care professional, I want you all the time and forever, be it the nurse or be it the home care agency.'

AF: That's right. Those are the qualities patients and families are looking for in their home care professionals. You asked Mark earlier, "Do you provide training to help your staff to provide sensitive and supportive care?" Yes, there are training sessions, and they are helpful. But experiencing some of the same feelings patients live with can be even more helpful. As strange as it is to think of September 11 as having any kind of positive impact, along with the higher

prevalence of post-traumatic stress disorder, especially in New York City and Washington, researchers also reported many people experiencing unexpected positive consequences in the wake of those attacks. Many reported closer relationships with their family members and a greater appreciation for every day. To further the parallel with the tragedy of September 11, the nurses and aides were affected by this trauma, too, along with everyone else in the country. At the time, I remember watching the news on television while staying with Jack in the pediatric intensive care unit—Jack had spinal fusion surgery a few days after 9/11—and I thought to myself, “Now, other people can understand what it feels like to be us.” There was a lot of talk that week about survivors and bravery and courage among the citizens and firemen and police officers in New York and Washington, and all of that was true. But as I sat there watching the news, it occurred to me that right there in the hospital were also many people—among the patient population—who were survivors every day, people who have survived and have been brave for a very long time. There’s a lot of bravery in that group; my little boy was brave after that surgery and he’s been brave for eight years now. There’s also a lot of courage shown by the nurses who walk into homes and know how to respond in an instant when their patient has a medical crisis. It takes courage to be a home care professional and to assume the level of responsibility that comes with providing care to a medically-fragile child like my son. Again, my family didn’t choose to be in this club, and the country didn’t choose to be attacked on September 11. But as a result of these painful experiences, there may be an unexpected opportunity to connect, to relate to, to identify with the experience of a vulnerable family when you’ve been exposed to a difficult situation that interrupts your own sense of security. And the sensitivity to those feelings—having experienced those feelings, too—may allow you to develop a deeper understanding and connection with the world of your patient.

JEM: Imagine for a moment the patient is here and the nurse or aide is here. What would you say to the two of them, as the nurse or the aide is going to be providing long-term services for to a patient. What would be your bottom-line message to these two people?

AF: My bottom line message would carry a theme of interdependence. My message to these two people would be, ‘We’re all in this together. We all have our roles—as providers, as family member, as patients, as administrators, as supervisors. If we work together and support each other’s efforts, the patient will be well cared for.’ Just as the health care industry is weathering times of uncertainty; a nursing shortage, spiraling costs, and malpractice concerns, the country as a whole is experiencing uncertainty as a result of terrorism, military engagement, and a weakened economy. We’re all in this together, so we need to look after one another. We’ll all be better off if we do.

JEM: Mark, what would your message be to these two people?

MB: Well, the message to the nurse or to the aide would be the one I normally give which I learned from a Dr. Winston. I was member of our local non-profit hospice back in 1980, and was in the first volunteer class. He came in as a physician, and, I thought I was going to learn all about medicines, pain and the science of it all; but he said, “I want you to remember one thing as soon as you knock on the door before you go in the house—show love.” So I tell all the nurses and aides to show love, that connection demonstrating you understand that person and you’re there for them. When you show your client love, they will feel safer and more secure and know they can depend on you.

Mark Baiada is the founder and President of Bayada Nurses, headquartered in Moorestown, New Jersey. He can be contacted at mbaiada@bayada.com. Albert Freedman, PhD, is a psychologist in private practice in West Chester, Pennsylvania, and a consultant to Bayada Nurses. He can be contacted at al@drfreedman.com.

About the Authors: Carol A. Trueman is senior counsel and vice president for administration for the National Association for Home Care & Hospice. She can be reached at cat@nahc.org.

James E. Murray is deputy counsel for the National Association for Home Care & Hospice. He can be reached at jem@nahc.org.