

WORCESTER medicine

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Guest Editorial: Care of People with Disabilities

Anne T. Kane, RN, Ph.D.



Anne T. Kane, RN, Ph.D.

Care for people with disabilities is common because disability is a common experience. After all, some 18 percent or more of Americans not living in institutional settings are disabled (Brault, 2012). Despite that fact, providers may not have specific preparation or experience caring for members of this population, especially outside of specialty

care settings, such as after discharge from a rehabilitation facility. In addition, meaningful access to care is often limited. Patients, families, providers and others are all potentially our teachers. In this issue of *Worcester Medicine*, we are pleased to present some perspectives on this important area of health care and provider education.

We know that disabilities may be physical, cognitive and/or mental, and they may occur anytime, from earliest fetal development through old age, from causes known or unknown, spectacular, accidental, intentional or insidious. The contributors to

this issue remind us that in every case, caring for people with disabilities taps our humanity. That theme is threaded through the experiences patients, families and providers share here. In their stories, we read that compassion and respect need to visibly animate our practices, as well as our policies and standards, perhaps even before we offer our first professional expertise, else we may do harm.

Janet Sweeney-Reno's honesty holds real examples of provider encounters up to the light of parental concern to illustrate how inclusiveness and compassionate listening are integral to care. Lindsay Romo's "Caring for Karen" tells us how her family's life changed when her aunt came to live with them after a permanently disabling illness. Karen herself advises providers, "Treat me as any other adult who needs help."

Ann Donoghue Dillon's life experience and professional skill come across in her "favorite questions" and "lessons learned along the way," which offer valuable instruction. I am fortunate to know Ann and can attest that, as her article suggests, she lives vibrantly by the principle that we are all in this together. Consider asking those questions and taking time to browse the

web resources she suggests. They are for all of us.

Deborah Armstrong identifies resources adults with incomplete spinal cord injury find helpful years after discharge from specialty care and what they would like primary care providers to know about their care. Reza Ghomi describes her learning experiences as a medical student paired with a full-time staff member at The Evergreen Center in Milford, Mass.

A colorful advertisement for Emerald City Indoor Gardening Supply Center. The background is a vibrant green and yellow pattern. The text is in various fonts and colors. At the top, "EMERALD CITY" is in large, bold, white letters with a green outline. Below it, "INDOOR GARDENING SUPPLY CENTER" is in smaller, green, sans-serif letters. A cursive script below that says "Create your own indoor garden with ease...". A list of products follows: "Complete Hydroponic Systems | Lighting Set-Ups | Bulbs & Ballast Organic Nutrients and Additives | Seed Starting and Cloning Coco | Organic Soils | Rockwell Irrigation | Pots and Containers Water Filtration | Tents and Tarps | PH/EC/TDs Meters". At the bottom, the address and contact information are listed: "51 Main Street Westminister, MA | 978-668-5393 | Emeraldcitygrowstore@gmail.com". There is a small graphic of a greenhouse on the right side.

Challenge is integral to the experience of what we call disability among patients, families, providers and communities. David Crandell's article describes some of the challenges faced by Boston Marathon victims admitted to Spaulding Rehabilitation Hospital, and the challenges faced by the specialized teams providing their care. One of the most striking ~ and perhaps lesser-known challenges ~ in that care was the complex communication required of impressively arrayed provider teams working with patients and their families. Jayna Turchek, director of Human Rights and Disabilities for the city of Worcester, describes Worcester's civic resources for reducing access challenges for people with disabilities, such as expert consultation on accessibility plans, technical support and public trainings. Training is available, for example, to teach an organization's staff principles of communication for their work with people with disabilities. Given what other contributors to this issue tell us about their experiences of provider communications, that offer might be especially timely.

We are grateful to our contributors for what they've shared with us on these pages, and we hope this issue supports us all as people living with disability.

Anne T. Kane, RN, Ph.D. is an assistant professor at the University of Massachusetts' Graduate School of Nursing in Worcester.

Reference:

Brault, M. W. (2012). *Americans with Disabilities 2010: Household Economic Studies Current Population Reports*. Available at <http://www.census.gov/prod/2012pubs/p70-131.pdf>



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Rehab Strong: Ongoing Efforts to Help Boston Marathon Bombing Survivors Heal

David Crandell, MD



David Crandell, MD

The early images from this year's Boston Marathon Bombing (BMB) were numerous and horrific. Cameras poised to capture the victories of those runners crossing the finish line with celebrations of families and friends were replaced with images of pain, anguish and fear. Some of these haunting images seem etched in our collective psy-

che. Mercifully, the finish line and the surrounding area, which had become a vast crime scene, then a fitting memorial, has now seen a Red Sox Championship parade, including a moment of silence for those lost and injured. Boylston Street has rebounded, but some of those injured just a little more than six months ago continue in a daily effort to recover.

The total number of those injured at the BMB eventually topped 265. As the initial reports from the treating physicians of Boston's Level 1 trauma centers began to be released and analyzed, it became clear that the two bombs placed among cheering spectators were designed to inflict maximum terror and catastrophic injury. If not for the heroics of many first responders, emergent resuscitation on the scene and transport via Boston EMS and other makeshift vehicles to all of the city's waiting trauma teams, many of the victims would not have survived. With the combination of the severe polytrauma from the blasts, including traumatic amputation(s), it was clear that many of the BMB survivors would need inpatient rehabilitation. A total of 33 patients, ages 7-71, were eventually treated at the new Spaulding Rehabilitation Hospital (SRH) in Charlestown.



Photo Credit – WBUR Radio

It took just five days for the first of the BMB survivors to be admitted to the SRH. All of the BMB patients were admitted to the Comprehensive Rehabilitation Unit (CRU) or the pediatric program. SRH quickly became the new base for healing and rehabilitation to continue. This state-of-the-art facility, patient-focused throughout its design, now had its initial charge of helping these extraordinary patients and their families through extreme loss, pain and uncertainty. The CRU became a place of daily gains, measured progress and reunions, some weeks in the waiting. Some patients and their family members were reunited for the first time, as some had been sent to different hospitals. The CRU was able to accommodate a mother and daughter in adjacent rooms, as well as brothers, brother/sister/girlfriend, and husband and wife. Beautiful sunny spring days, lots of natural light, sweeping views of the Boston Harbor and skyline and therapeutic garden spaces all contributed to a palpable Boston Strong effect.

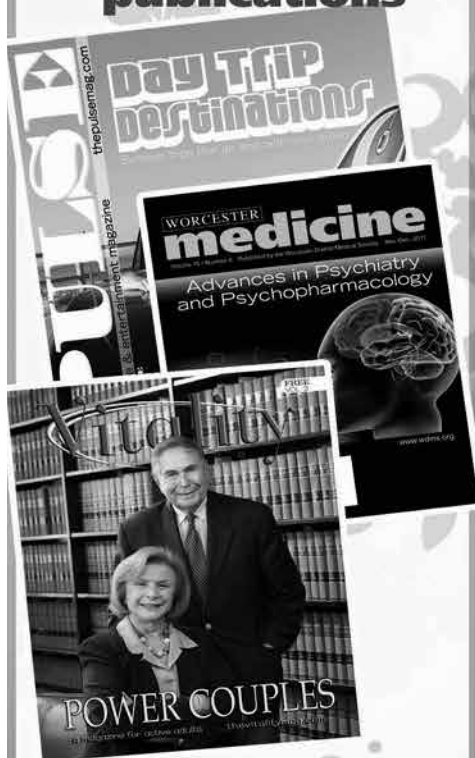
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All of the BMB patients sustained lower limb polytrauma, including injuries to bone, nerves, vasculature and soft tissue. Several had burns, and 15 patients had major lower limb amputations. These traumatic amputations and complications are similar to those acquired during military conflicts. Some of the BMB survivors required multiple surgeries for debridement, removal of shrapnel, skin grafts and free flap procedures with no weight bearing, complicating early rehabilitation efforts. Three have developed heterotopic ossification in their residual limbs, complicating their prosthetic fit and comfort. Two amputees required extended courses of antibiotics due to localized infection.

When working with the BMB patients, interdisciplinary team members needed to be reminded to speak loudly and clearly. Almost all of the patients experienced some hearing loss from the blast, as well as post-concussive symptoms and signs. All the patients demonstrated a range of acute stress reactions, requiring a patient-specific treatment plan. The SRH CRU team continued to deliver high-quality medical and rehabilitation care under the media spotlight. This required highly effective communication among team members, including psychiatry, nursing, physical therapy, occupational therapy, speech language pathology, therapeutic recreation, social work, care coordination, psychology, psychiatry, internal medicine, infectious disease consultation, renal consultation, pharmacy, laboratory services, nutritional services, pastoral care, research technologies, wound specialists, adaptive sports, secretarial staff, transportation, environmental services, security, communications, development, administration, acupuncture, Reiki, educational staff and materials management. Twice-weekly team meetings ran long but resulted in excellent interdisciplinary functional outcomes, including home discharges for all the marathon survivors.

Support from the community was a major element in the healing process of the BMB survivors. Visits from the Semper Fi Fund and Warrior Transition Unit veterans, former patients, Amputee Coalition peer visitors, local celebrities and sports figures, Paralympians and movie actors and actresses were incredibly positive and inspiring, giving the survivors and their families messages of encouragement and hope. I observed no greater impact than when former Congresswoman Gabrielle Giffords visited the CRU while in Boston to receive a Profile in Courage Award from the Kennedy Library. The community support in the form of prayers, money, resources and services has been incredible. The Boston Firefighters, Police and EMS unions just presented SRH with a check for close to a quarter of a million dollars for ongoing BMB rehabilitation efforts. I hope that this support will continue to be there over the long road to recovery.

So far, the BMB survivors and their families, as a group, have been doing well. But now, even after their inpatient rehabilitation is complete and many continue in outpatient therapy, there are clearly good days and bad days. Some have required additional surgery. Most have recovered from their initial acute traumatic reactions, but some are still having a difficult time adjusting to what has happened and are being treated for Post Traumatic Stress Disorder. A few are back to work.

Thankfully, I have new images to compete with the ones from April 15, 2013. These include first steps, first dances and a first pitch at Fenway Park. I hope I see continued rehabilitation and life success as I follow these patients in the months and years ahead.

David Crandell, MD, is the medical director of the Amputee Program at Spaulding Rehabilitation Hospital in Charlestown.

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Providing Meaningful Access to People with Disabilities

Jayna Turchek, Esq., City of Worcester Director of Human Rights and Disabilities



Jayna Turchek, Esq.

Providing everybody with meaningful access to services is a multi-pronged approach that requires developing awareness and providing education and resources to better inform both decision-makers and front-line staff.

The degree to which we collectively can bring about full and equal participation in all aspects of life in the city of Worcester for all persons with disabilities depends, in large part, on our understanding of the myriad of challenges faced by persons with disabilities on a daily basis and our ability to educate, mobilize and build trusting relationships and collaborations.

As the Americans with Disabilities Act (ADA) coordinator for the city, I receive complaints from the public about physical and programmatic access barriers. Physical barriers are the most obvious type of access complaint, and when property owners are not well informed about their responsibilities, they may be wary of an initial conversation. This is the case largely because of the fear of the pricetag that is assumed or known to be attached to removing the barrier. Some barriers do not have simple fixes due to the cost or geographical or architectural limitations of the space in question. Others may be exceptions to the law, where variances have been obtained or could be obtained, which may be the case for some historical properties. And others may meet the letter of the law but not necessarily

the intent of the law; for instance, an adjustment might meet the measurements, but is it practical and helpful for the user? Whatever the case may be, fear of the known or unknown need not be the motivating factor when conversations about accessibility arise because there are good resources available to assist you, whatever the situation.

Sometimes an openness to a conversation about the individual's needs and the organization's readiness to make reasonable accommodations to practices or policies is enough. It goes without saying (but perhaps a reminder is helpful) that everyone wants to be understood and treated with respect. The time to have that conversation can be anytime. It is also important to be proactive and not wait for a problem to surface. As service providers, it is important to regularly review our policies and practices to ensure that a reasonable accommodation notice is made known to all we serve. The ability to communicate in alternate formats with the public is also essential, as well as making sure websites are accessible to individuals who use adaptive software to read or open webpages and other online documents.

Once a review is completed, you may find changes are necessary. When any organization plans for changes, it is critical to gain an understanding of how changes will impact different populations. Worcester's Commission on Disability is one place where organizations within the city can turn to get input on accessibility plans, policies and programming. This advisory commission meets monthly at Worcester City Hall, and a majority of the members are persons with disabilities. To find out

more about the commission or if you or someone you know are interested in becoming a member, go to worcesterma.gov/boards-commissions

In an effort to provide greater awareness and increase accessibility throughout our city, Worcester's Office of Disabilities is available to provide technical support, resources and referrals for individuals or organizations that have questions about accessibility standards. Throughout the year, we provide free trainings to the public on a range of disability-related topics. Additionally, staff are available, upon request, to provide communication etiquette trainings. We know that effective services and programming starts with appropriate communication. The training program, designed to assist groups in understanding basic principles of communication when working with persons with disabilities, can be tailored to meet the needs of your operation and can range from 30 minutes to one hour. We seek to engage your staff about how to serve and/or interact with people who have disabilities. This is an excellent opportunity to ask questions, share experiences and learn from one another. At the conclusion of the program, we provide additional resources and referrals to better assist your operations. To learn more or to schedule a training, contact Dawn Clark at 508-799-8483 or clarkde@worcesterma.gov.

Together, we can work to improve understanding and accessibility.

Jayna Turchek, Esq., is the City of Worcester director of Human Rights and Disabilities.

Roots of Resilience

Ann Donoghue Dillon, M.Ed,OTR/L

As a child growing up in Worcester many years ago, some early experiences with disabilities ~ right in my own neighborhood and local church ~ began to shape my beliefs and values. Seeing a young man with disabilities at worship or playing with neighbors who had some differences, we didn't know the "labels," and it didn't really matter. My mother often substitute taught in a "special" school in Worcester, bringing home warm and fun-filled stories that became part of my personal history and my roots in understanding disabilities.

Eventually, going to college, becoming a pediatric occupational therapist and working in the Worcester area for many years allowed me insights and valuable life lessons. Families welcomed me into their homes to offer support, whether to an infant discharged from the hospital with risks for developmental concerns or a child experiencing a known disability. They taught me about the importance of finding strengths, creating hopeful and positive lives for their children and working with what was reality in the context of each unique family. Little did I know that they were not only teaching me how to become a better professional but were preparing me to become a mother.

When my daughter, Brie, was born in 1985, life changed quite unexpectedly. We learned in the hospital that she had a rare syndrome, would have many medical and developmental problems, and would die before the age of 2. With all my years of experiences and training, nothing prepared me for the deep and gut-wrenching news that we would lose our beautiful baby. In a strange shift in perspective, the disabilities didn't matter so much, but the thought of losing her was devastating and took up so much space in our thoughts and hearts. That loss of hope stopped us from looking forward to a life with her in our little family.

But Brie was amazing. In spite of the prevailing opinions, she grew and developed! Yes, even with many challenges (feeding tube, wheelchair, surgeries, seizures, illnesses, etc.) as part of

her daily life, she went to the local school, was in regular classes, rode the regular school bus, became a Girl Scout, made her first communion, graduated from high school and even took some college classes. She taught so many people about resilience, living a normal life and being part of a community. When she passed away at age 25 several years ago, we got letters from friends and old classmates affirming what a great teacher she had been.

How did her life change me? The biggest change was about developing resilience. Looking back to my history and life experiences, adding in the present reality of what and who we had to support us, and coming up with a mindset and plan to get what we needed to move forward ~ those are all the things that helped me become more resilient, even to this day.

I really began to get my hope back and feel stronger when Brie was 3 years old. I attended a leadership training series for parents who also had children with disabilities in my new home state of New Hampshire. I began to understand that what we wanted for Brie was for her to be treated like our two other children, to have all the normal and typical life events, to be a part of everything our family and community offered. To be set apart and treated differently would be to deny her what we felt was just and fair. These realizations were the turning point in getting Brie to move from "special" to "regular," even if that meant we didn't have a perfectly formed plan!

Brie had a good life because we followed the path most traveled, a path that seemed closed at the beginning but one that opened up to us as we explored and strengthened our values and beliefs. We continually asked the question "What would she be doing if she didn't have a disability?"

So now, I try to teach some of what I have learned on this journey. I teach others about how to find their own strengths and resilience. I work with different teams to best convey the es-

sence of what leadership is and what they need to do to become stronger. In the New Hampshire Leadership Series, we help parents and individuals who have a disability to develop their leadership skills. In the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, one of 43 in the nation, I provide a family perspective in the seminar and mentor trainees who are also parents in becoming leaders in the field. I edit for the New Hampshire Institute On Disability's Genetics Education Material for School Success (GEMSS) website so that readers will find the educational information more parent and teacher-friendly.

My favorite questions to our aspiring leaders are:

What do you stand for?

What is keeping you from doing more?

They are questions that I even keep asking myself, and they can challenge us all to keep growing and looking for more and better ways to be involved!

Certain highlights rise to the top in the lessons learned along the way:

- Inclusion is a great beacon, the best starting point!
- Everyone needs a voice. Be their champion and help them find it!
- Rekindle hope after a developmental diagnosis.
- Believe that the child is right, whole, perfect. The "Disability is Natural" work by Kathy Snow provides some great insights.
- Assume competence, even if you haven't heard their voice yet.

- Independence needs to start early ~ aide and then fade in education, home, etc.
- Look for partners in medical, educational and spiritual communities ~ an ally, a reliable sounding board and honest reflectors.

Even though Brie's life on earth is over, her influence remains strong. A former third-grade classmate of Brie's, now an adult, told her nurse that she wanted a "life like Brie Dillon's" for her son, who experiences disabilities. Her roots have spread far and wide, and I am forever changed for being part of the journey!

Resources:

1. Institute on Disability, University of New Hampshire, iod.unh.edu
2. NH Leadership Series, nhleadership.org
3. NH Leadership Education in Neurodevelopmental and Related Disabilities (LEND), mchlend.unh.edu/home.aspx
4. Genetics Education Material for School Success (GEMSS), gemssforschools.org
5. For Massachusetts Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, umassmed.edu/shriver and <http://www.childrenshospital.org/ici>
6. For Leadership opportunities for parents in Massachusetts, mfofc.org/events/fls/2014-northeast-and-metro-boston.pdf

Ann Donoghue Dillon, M.Ed., OTR/L, is a clinical assistant professor at the Institute on Disability, University of New Hampshire. She is coordinator of the New Hampshire Leadership Series, on the faculty of the New Hampshire LEND Program and contributor to the GEMSS Project. She is currently serving on the New Hampshire Governor's Commission on Disabilities. She formerly worked in the Child Development Services at University of Massachusetts Medical Center.

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Traveling Through Uncharted Territory: Aging with an Incomplete Spinal Cord Injury

Deborah Armstrong, Ph.D., RN

For centuries, individuals who suffered a spinal cord injury (SCI) were destined for early death. Due to advancements in medical science over the past several decades, individuals with SCI are now living well into middle age and beyond.¹⁻⁵ This group includes people with complete transections of the spinal cord, as well as those with incomplete injuries, where some sensation and/or motor abilities remain intact. As this population lives longer, it is becoming clear that aging often brings an assortment of physical changes that can increase existing limitations and threaten hard-won independence.

In my recent dissertation research, I explored the physical changes experienced by people aging with an incomplete SCI. Because so little is known about aging with SCI, I chose to go straight to the experts ~ the people who are living this experience. I interviewed men and women with varying levels of disability related to their incomplete SCI. Some participants were able to walk after their injury (though most required some form of braces and/or canes for walking support), while others were dependent on wheelchairs post-injury. The common thread across all participants was that they were between 35 and 65 years old and had lived with their SCI for at least 15 years.

A common theme that arose from all of the participants in the study was the sense that they are travelling through uncharted territory. They have received very little guidance from others, including their health care providers, about what to anticipate as they get older. Many individuals who experience an incomplete SCI receive excellent acute care in trauma centers, followed by intense rehabilitation overseen by neurologists, physiatrists and other specialists. During that rehabilitation period, they are carefully guided through the process of regaining some motor function and learning to accommodate their new limitations. However, the changes that come with aging occur years after they are discharged from specialty care. Most of the study participants indicated that

they received little to no information from their previous or current health care providers about aging with an SCI, and several participants stated that they often needed to educate their physicians about SCI. This is consistent with studies that indicate many primary care providers are unfamiliar with the needs of individuals aging with a SCI.⁶⁻⁷

The individuals who participated in this study were clearly seeking information and guidance about aging with an incomplete SCI. In the absence of expertise from their health care providers, their primary source of information was the Internet. Some of the agency websites they mentioned as helpful were the Christopher and Dana Reeve Foundation (christopherreeve.org), the Craig Hospital (craighospital.org/Left-Nav/Specialty-Services/SCI---TBI-Health-Info/) and Boston Medical Center's Stepping Forward ~ Staying Informed program (bmc.org/spinalcordinjurycenter/consumereducation.htm). In addition, they mentioned two web-based discussion boards as information sources: the Spinal Cord Injury Network (spinal-injury.net/spinal-cord-injury.htm) and the Care Cure Forum (<http://sci.rutgers.edu/vb5/>).

Current research shows a high use of the Internet as a health information source for individuals living with SCI.⁸⁻¹¹ However, this does not negate the need for individualized guidance from health care providers. From this study, here are a few ideas of what individuals aging with an incomplete SCI would like from their health care providers:

Be informed and keep me informed. There is a growing body of research that examines various aspects of aging with a SCI.^{3,4,12-16} Community-based primary care providers with increased knowledge about the physical changes common in individuals aging with an incomplete SCI are better equipped to help their patients through health-promoting and preventative strategies, as well as provide appropriate care when changes do occur.

Encourage me to be vigilant. An individual aging with an incomplete SCI needs to be attentive to his or her body on a day-to-day, moment-by-moment basis. One study participant described living with an SCI as a “full-time job ~ with no breaks.” This vigilance is important in assessing or monitoring for potential changes, as well as in managing changes and preventing complications. For example, individuals need to carefully monitor for changes in bowel elimination patterns and use an effective combination of medications, dietary practices and other bowel stimulation methods to avoid constipation and/or incontinence. Other specific areas that require vigilance are monitoring skin integrity, maintaining appropriate urinary tract care and controlling body weight.

Help me anticipate the consequences of my choices. There are many complex decisions that need to be made by individuals with SCI that may affect other aspects of their health. A purposeful choice made by the individual to maintain health and/or independence may have a negative impact on another aspect of physical function. For example, one participant reported that he has experienced a significant increase in skin issues during his middle age years and attributed that change to the fact that he has chosen to stay up in his chair because it is best for his lungs. Others described situations in which their choices to remain active resulted in chronic pain and associated wear-and-tear injuries. While many people might consider the consequences to be “worth it,” guidance in that decision-making process can be valuable.

Remind me about the profound impact of small changes. What might be considered part of “normal aging” for able-bodied people may have a much more significant impact on individuals living with SCI than on the general population. For example, gaining 5 to 10 pounds might require an able-bodied person to buy new pants. That same change in an individual with a SCI is likely to impact their ability to transfer onto a toilet or shower chair, ultimately threatening their independence. Additionally, weight loss is particularly challenging for individuals aging with a SCI. Exercise options for a person with a SCI are often limited for ambulatory, as well as non-ambulatory, individuals. Being aware of the impact of small changes can help encourage vigilance.

As health care providers, we have an opportunity to collaborate with our patients who are aging with an incomplete SCI to prevent some loss of function and plan for unavoidable changes associated with aging.

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Memorable Encounters

Janet Sweeney Rico, MBA, NP-BC, Ph.D.

“I don’t have all the answers, but most important, continue to love her as you do. You both are doing a wonderful job caring for her. She looks so happy!”

The neurologist sat close beside me and held Lauren’s tiny hand. We knew something was wrong with my daughter soon after the uncomplicated delivery, but nothing could prepare us for her brain’s imaging results: microcephaly... future unknown. We had seen the pediatrician a few weeks prior but remained hopeful that this initial news was just a bad dream.

We began our journey parenting a child with global delays with the realization there were no clear answers or even a definitive diagnosis. Our love and her happiness were the priority in her plan of care. I hear the neurologist’s words so often, especially during those difficult periods.

The past 22 years have been cruel at times. Lauren would not walk or talk, and the seizures would become more difficult to control. We learned she was legally blind, and her joy in eating suddenly stopped. Function declined with worsening contractions. She had numerous hospitalizations for seizures, pneumonia and orthopedic surgeries, and we became increasingly aware of her medical fragility and our need for constant vigilance. Orthopedics, ophthalmology, cardiology, gastroenterology, physiatry, surgery, genetics and palliative care specialists were slowly added to the list of support, along with our beloved pediatrician, neurologist and nurses. Lauren has had outstanding medical care, and the majority of her physician visits have been wonderful. She is still with us because of this care. This article will share some of the most memorable of these encounters.

The initial news regarding Lauren’s diagnosis came abruptly via phone one evening after a pediatrician’s visit earlier that day. My husband was away on business and I was home alone with 6-month-old Lauren and 2-year-old Michelle. The visit was distressing. Her head circumference showed no growth, and she was not on target with her developmental milestones. I can still hear the doctor’s abrupt presentation done impersonally over the phone. “The X-ray did not show craniosynostosis. This means she is microcephalic. We will schedule a neurology appointment as soon as possible.”

It was bad news, of course, but the way it was presented left me feeling more alone and frightened as I encountered this new world of “special needs” parenting. I wish there had been more thought into the fact I was alone. I wished she had been with me to give me the news.

Lauren began to have difficulty with adequate fluid and food intake and I reluctantly scheduled a GI appointment to discuss G-tube placement. While I maneuvered the wheelchair on the van lift prior to the visit, a man quickly ran over to help. It was then that we met Dr. H., one of the most compassionate and insightful physicians Lauren has encountered. He gently encouraged me to move forward with placing the gastrostomy tube, with the reassurance that I was doing all I could do as a mother to feed her. He then gave me a prescription. It simply read, “Date once a week with husband!” He took the time to listen without the distraction of EMR, phones, pages or the patient schedule. He spoke directly to Lauren and he included her in the conversation. He listened to my issues in feeding and caring for Lauren and acknowledged the almost symbiotic relationship required to care for a child who is non-verbal

and unable to do anything for herself. The visit with him was polar opposite to an internal medicine visit I had the following week for my worsening back pain. The lifting was taking its toll, but there was no inquiry into my activities of daily living or stressors. I quickly found a new provider!

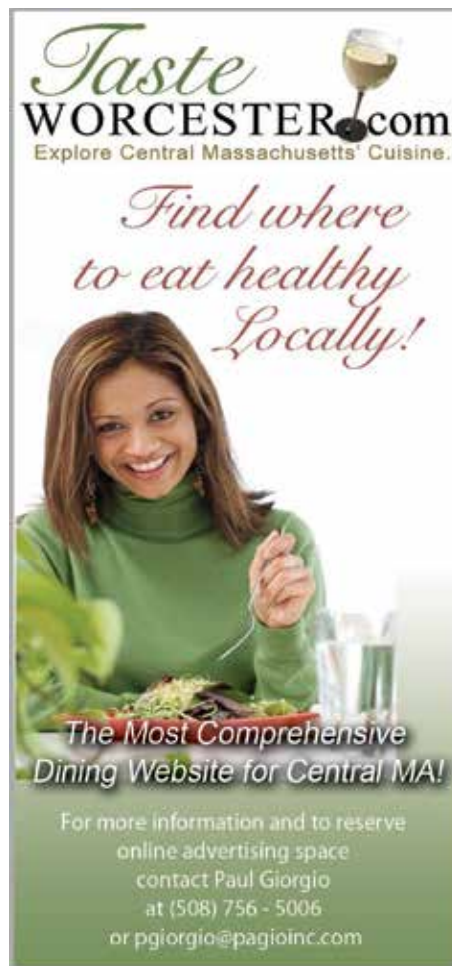
Drs. Stacy Kennon and Andrea Urban have been our lifeline, and having provided primary care in the past, I know how busy they are. These pediatricians have certainly gone beyond expectations, and we are forever indebted. From drafting prior authorizations to meeting with intensive care physicians, they have been there to guide us in maintaining Lauren's quality of life and our sanity! They have provided seamless continuity with specialty practices, called us themselves or had support staff call to check in, advocated for needed services and handled precarious medical situations with competency and expertise.

There have been very few physician encounters that have reminded me of the need to reinforce the importance of listening, patience, compassion, openness and self-awareness. Unfortunately, these encounters are difficult to forget. Recently, a physician who did not know Lauren came into the room and was openly distressed after seeing Lauren sitting uncomfortably in her wheelchair. She then abruptly commented that it would be difficult to see her without her medical records on site. I hadn't even had the chance to tell her why we were there or that I could easily present the medical history. A resident physician inquired whether I had undergone an amniocentesis and looked surprised to hear I did not. He was even more surprised to learn it would not have told us anything! Although I understood his curiosity, the question made me think he wondered why she was born. My older daughter went with us to many of Lauren's medical appointments. After one very unsatisfactory visit, she turned to me and said that I should not take Lauren back to see that doctor. At the tender age of 11, she surmised that this physician was not interested in caring for Lauren since she never spoke directly to Lauren nor did she acknowledge Michelle's presence in the room. Michelle further noted that she was on the computer the entire time!

Physicians have been there for us over the past 22 years, through the good times and the bad. Memorable and cherished physicians consider Lauren as a unique individual who has individual needs requiring creativity and vigilance. Their presence alone is therapeutic. They listen, think holistically, have a non-judgmental attitude, consider quality of life foremost, recognize caregiver burden and maintain humor and realism. They work well on a team in providing care and consider input from all involved. They are self-aware and recognize stress and do not make it harder for us when they are having a hectic day.

We have been blessed to have the pediatric physicians we have caring for our beloved daughter. Our next challenge is to transition her from pediatric to adult services. We are hopeful we will have the same wonderful team of dedicated adult physicians!

Janet Sweeney Rico, MBA, NP-BC, Ph.D., is a nurse practitioner in the emergency department at Massachusetts General Hospital. She is the former director of the Family Nurse Practitioner Program at Simmons College, Boston.



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Caring for Karen

Lindsay Romo, MD/Ph.D. candidate, University of Massachusetts Medical School

Before I knew about seizures, my family's life was changed by one. In the early summer of 2005, my aunt, Karen, was rushed to the hospital after having a grand mal seizure. There, via a failure of the system, a few days went by before an internist noticed a small lesion on the CT, rechecked the lumbar puncture and correctly treated her for herpes encephalitis. By then, the irreparable damage was done. When my aunt woke up after three days in a coma, she didn't know who she was, what any words meant or how to speak. Over the next several years, she, and my family as caretakers, had to learn to live with her intellectual disability. I sat down with Karen and my parents, with whom she lives, to ask about what their life is like now.

Karen (my aunt): "When I woke up, I was very glad to have my mother and sister with me because I was very scared. They were the only family members I recognized. My occupational and speech therapists helped me to learn to talk and manage my money. But sometimes, after I started working at Safeway again, I would cry in the bathroom during the day because I was so overwhelmed.

"I am frustrated that I need to have help. I am aware of what I have lost. It's hard to live with my sister because I have a hard time finding things, and she gets very impatient with me. I feel bad that I can't be independent, and it's hard to deal with that change. I used to love to sew ~ I sewed people's wedding gowns ~ and I can't sew anymore.

"It's very hard for me when people have expectations of me that I can't fulfill. I want my doctors to involve my family, because it's important for me to have a lot of support in my care. Health care professionals should know about my past but treat me as any other adult who needs help."

John (my father): "Karen has gone through three phases. First, she had to be taught like a child. Second, she was learning quickly and had a sweet personality. Third, all of her old bad tendencies from before the injury came back exaggerated. She can be very self-centered and gets prideful and oppositional if you try to point it out to her.

"I feel like I'm constantly walking on eggshells. It's very challenging to maintain patience. It's hard not to be angry, but I know that underneath she can't help it. It was so good to be able to help her right after she woke up, but now, it is very unsatisfying because she could still learn things, but she won't accept help and she often lashes out.

"It is hard having her live with us because it is very distracting from my marriage. A lot of energy and focus goes into her care instead of into Sheryl. However, I have grown more sensitive to the problems of people with brain damage. In my practice [as a medical geneticist], I have worked with a lot of people with mental retardation, but those people grow up with it and learn to cope. For Karen, everything just suddenly changed. I'm now more aware of that challenge, and I respect how far she's come.

"My advice to health care professionals taking care of people like Karen is to know that there are unanticipated consequences to things you say or do. You need to teach with multiple repetitions. Don't always expect gratitude from these patients, either, and just know that they may have a hard time looking out from within themselves."

Sheryl (my mother): "I blame myself for so much for not standing up to the doctors initially. I knew something was wrong besides a seizure disorder. When she woke up and we took

her home, she was afraid to sleep, so we all slept with our doors open. She would sit in front of the blank TV and stare at it because she didn't know what it did. She was sent home from vocational and speech therapy with worksheets, and I just sat there with her for hours every day, doing worksheets and flashcards. It was exhausting. I had no time for myself or for anyone else for a year.

"She was initially so kind and loving, but then one day, she started crying because she remembered what she couldn't do, and she wasn't sure if she wanted to live. It was clear she would never get back to who she was before, but she worked hard and improved a lot in the beginning, which was very rewarding.

"The better she got, the more angry and frustrated she became and the more she felt judged and picked on. Now, it's very hard to be patient because you have to tell her the same thing over and over. Sometimes, I get angry and yell at her. But I feel very, very sad for her and everything she's lost and the relationship that we have lost. There are times when I can't stand it because it's like living with a 2-year-old, but I could never imagine not doing it. I just feel this intense sense of loss for Karen and her normal life.

"Health care professionals should talk to Karen like she is their patient, not me. Treat her like an intelligent human being. It helps me, too, because when Karen feels more self worth, she is less angry and depressed. She understands more than the doctors give her credit for, and she is well aware if she is being disrespected.

"I just don't want to see her hurt anymore."

Lindsay Romo, MD/Ph.D. candidate, University of Massachusetts Medical School

Caring for Severely Mentally Disabled Children

Reza Hosseini Ghomi

MD Candidate, Class of 2014, UMass Medical School

Recently, I had the privilege of witnessing the integration of care services for children with severe developmental disabilities at The Evergreen Center in Milford, Mass. The Evergreen Center (evergreenctr.org) was founded in 1982 to provide educational services for children who could not function in a standard educational setting with their peers and had no alternatives. The model is holistic: Each classroom instructs up to eight children, who also live together in a community home. Students are paired with full-time staff members, who accompany the children both at home and at school. This individualized attention allows for continuity of care rarely found elsewhere.

Evergreen's guiding principles are social competency and normalization. Every day, students are given opportunities to function as members of their community, improving their abilities in language, activities of daily living and social and vocational skills. Staff members help their students develop these skills through the use of evidenced-based practices and interventions.

When I first visited Evergreen with Dr. Sheldon Benjamin, I was in awe, not only of the facilities but also of what the staff members were able to accomplish through their dedication to proven practices. In a moment that would cause me incredible stress and frustration (a child throwing a tantrum, for example), staff maintained their composure and intervened with the minimal redirection required to maintain safety, for both the child and those around him or her. At first, from my perspective, the goal of social competency seemed unattainable for many of these children; however, upon closer inspection, I realized that the success of the Evergreen model is nothing short of amazing.

For decades, Dr. Benjamin has made providing the highest level of care to the children of Evergreen his personal mission. His dedication to a population often marginalized is exceptional.

At each visit, we reviewed each patient's medical history and received behavioral updates through the use of accurate reporting of data presented in graphical form. These graphs allow for rapid assessment of changes in individual behavior over the preceding weeks and months. With each child on various medications ~ many of who are unable to communicate ~ the accuracy of data collection by the teachers and staff is paramount to monitor both therapeutic and adverse drug effects. Due to the patient's inability to participate in his or her treatment planning, great care was taken to assess adverse effects and adjust drug regimens, providing the lowest possible doses of medications while allowing the child to be as functional as possible. Many times, I found myself joining the cheers among the care team as we looked at a graph illustrating the decrease in self-injurious behavior from perhaps 1,000 episodes a month to 100, or even much less.

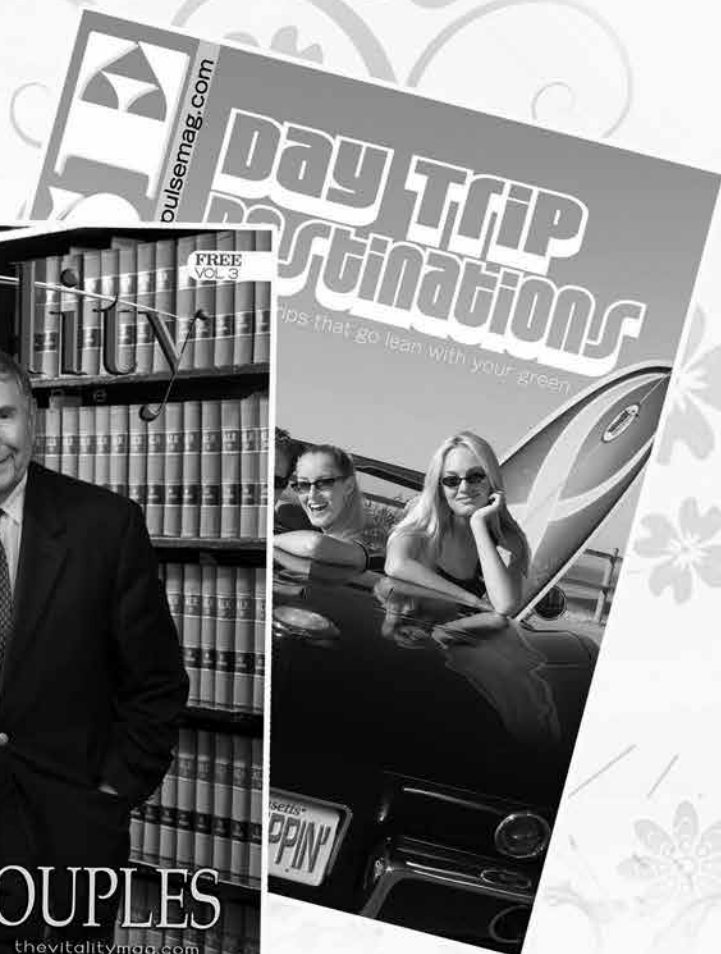
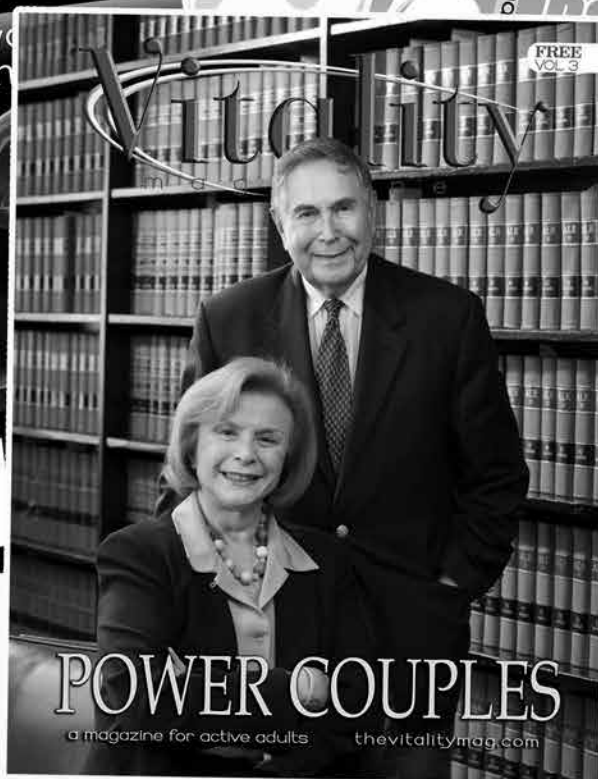
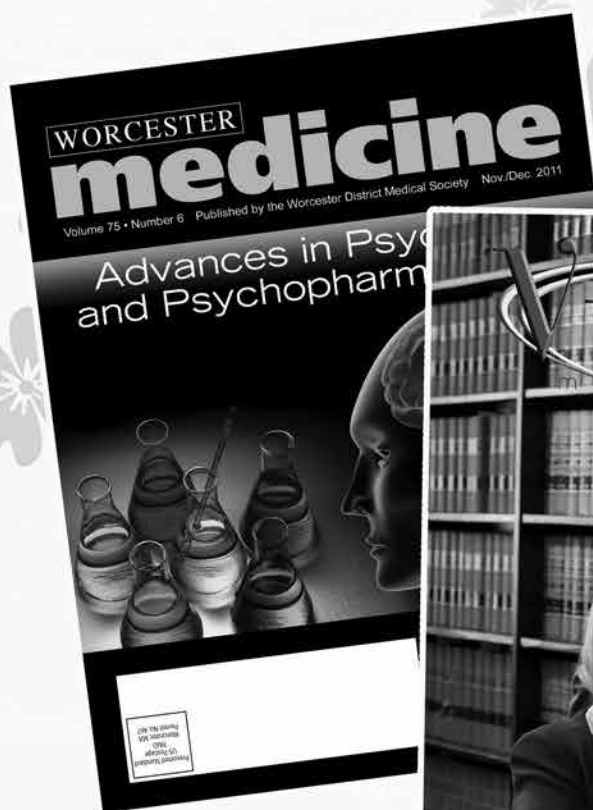
What was perhaps most impressive was witnessing Dr. Benjamin's rapport with each child. He knew every child's story. He knew their idiosyncrasies and the subtle ways they communicated. He greeted each child with a warm and genuine smile and completed whatever parts of the physical exam the child was willing to allow. My experience at Evergreen was invaluable, not only for developing my own comfort with and understanding of severe developmental disability but also for fostering future advocacy for a population in need. Dr. Benjamin's tireless work with this population is a testament to his dedication to practicing the highest level of medicine. It was an honor to help out at the Evergreen Center under his guidance ~ an experience I will never forget.

Reza Hosseini Ghomi

MD Candidate, Class of 2014, UMass Medical School

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**Albert Haddad, MD
(1917-2013)**

Dr. Albert Haddad died Oct. 1, 2013, at the age of 96. He was born in Worcester, one of 10 children. After graduating from North High School, he continued his education at Clark University and Albany Medical College. His post-graduate training was interrupted by military service during World War II, for which he was awarded the Victory Medal.

He went on to complete his residency training in orthopedic surgery, including subspecialty care for children crippled by poliomyelitis, and then returned to Worcester, where he engaged in clinical care for 40 years.

Dr. Haddad practiced primarily at Worcester City Hospital (WCH) during its halcyon years as one of the three most sought-after hospitals in New England offering a “rotating internship.” When the WCH closed in 1991, Dr. Haddad continued his affiliation with Fairlawn, Hahnemann and Memorial hospitals.

For recreation, he focused on physical fitness and sports, including golf. Well into his 90s, he was still skiing at Mt. Wachusett. Other interests were music ~ especially playing the harmonica (the lyrics of “Oh Danny Boy” appeared on his memorial card) ~ and gardening.

It is prophetic that the historic chapel at Worcester City Hospital served as the site for his memorial service. Constructed as a separate building at the turn of the 20th century, the chapel was “rescued” at auction, stored for many years and ultimately reconstructed, piece by piece, in the Beechwood Hotel by Dr. and Mrs. Charles and Janet Birbara. Known as the Maria Gill Wilson Chapel, it served as a most fitting sanctuary to celebrate the life of Dr. Albert Haddad. His memorial service included musical interludes on the harmonica. Dr. Haddad donated his body to the Anatomical Gift Program of the University of Massachusetts Medical School.

Doctor Haddad’s life was well lived because he served others so well.

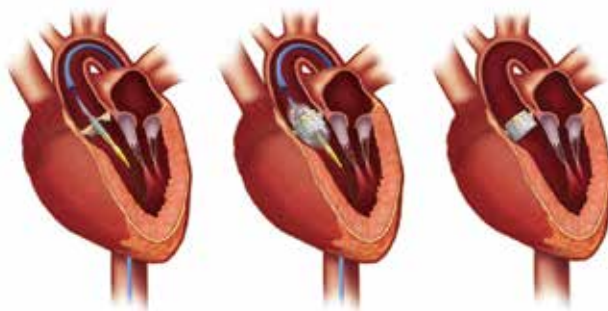
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