

A Physician's Perspectives on Guiding Care Givers

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Care givers can be an essential part of health care delivery for many Polio survivors, or for that matter anyone with a significant disability. As a specialist in Physical Medicine & Rehabilitation, I frequently help individuals with disabilities integrate care givers into their healthcare plans. Sometimes family members provide this care and other times caregivers are hired. Many provide significant physical assistance throughout the day beginning with bed to wheelchair transfers and assistant in the bathroom, as well as help with dressing, feeding, or hygiene. Others provide only occasionally assistance with specific physical activities or help to oversee medications and monitor safety concerns. Whatever the duties of the caregiver, the goals should center on meeting functional goals and safety concerns. Rather than being viewed as evidence of disability, a well-thought-out plan for utilizing a caregiver should maximize function, reduce the risk of injury, and minimize the need for hospitalization for nursing homes. Unfortunately, caregivers sometimes are not well directed and provide more "care" than is needed. As an example, it is not uncommon for individuals with a disability to allow caregivers to assume the responsibility for monitoring medications when they are perfectly able to manage. In delegating this or other responsibilities, the individual actually creates more of a disability and increases the risk of complications or chances of future decline in function. Therefore, it is extremely important for an individual utilizing a caregiver to be able to develop skills at directing care without surrendering their duty to take responsibility for their own life and wellness.

These skills may take time to develop. Additionally, some might perceive a fine line between directing care and being "demanding". This distinction became very clear to me during my first clinical position after residency in 1990. I managed a busy Spinal Cord Injury rehabilitation program that was located one floor above a pulmonary rehabilitation program. Individuals with high spinal cord injuries (with complete paralysis and inability to breathe on their own) would be admitted on the pulmonary rehabilitation program in order to manage their ventilators and then be transferred to the Spinal Cord Injury Program. Since they had complete paralysis of arms and legs, most of their physical needs were provided by others. While they were on the Pulmonary Rehabilitation Program, they were cared for by staff that usually treated elderly individuals with severe lung conditions. The model of care was closer to an acute hospital than a rehabilitation model of care. As a result, the staff on that unit would often "label" the young spinal cord injured patients as "manipulative". When the same patient came to the Spinal Cord Injury Program, we would see the same behavior as "directing care" and encourage them to refine their skills further. Our goal was to provide a team that could work together to meet the individual needs of the patient as expressed by the patient. This is a much more collaborative model than the "top down" approach to health care in acute care hospitals.

Perhaps my most memorable experience in witnessing an individual direct their care was when I met a Polio survivor who was ventilator dependent, yet worked full-time and traveled extensively. He employed an assistant who coincidentally had a history of traumatic brain injury and therefore had limited fine motor skills in his hands. We met when mutual friends organized dinner after a conference. The dinner was at the buffet at Caesar's Palace in Las Vegas. Within minutes after we met, we were both navigating the buffet line and he directed his aid to fill his plate with his choices including his favorite shrimp. I was impressed with how smoothly they worked together. Yet, I was most impressed after we set down and I found out that his aid was unable to peel the shrimp he had obtained. While I cannot remember the exact words, I

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remember being gently asked and told at the same time to peel the shrimp. Although I was a stranger to this Polio survivor a few minutes earlier, he had absolutely no reservations in requesting my assistance and did it in a way that made it perfectly clear it was a reasonable request that I should comply with and for which he was grateful. There was no awkwardness and there was no friction. It was clear that I would peel his shrimp and we would carry on with our conversation without missing a beat. His confidence combined with his personal charm and interpersonal skills serve as a perfect model for an individual with a disability to direct their care. While many individuals fear being a “burden” I can tell you that I still recall that interaction almost 20 years ago because it was not even remotely a “burden” or inconvenience and I truly felt grateful to be able to provide assistance in such a relaxed way. It has been my experience during my career in Physical Medicine and Rehabilitation that the best way to eliminate stress and awkwardness with caregivers is for the individual in need of service to be confident, direct, and appreciative. In the vast majority of circumstances, this leads to the care provider feeling relaxed and even blessed that they had the opportunity to help. There will always be individual caregivers who lack integrity or appropriate motivation to be serving

in that capacity. Nevertheless, the vast majority of caregivers have a heart to serve, are willing to follow directions, and have a desire to be appreciated. Rather than being a “burden”, this relationship can be a blessing to both caregiver and care receiver.

Lastly, I thought I would comment on the notion of “independence”.

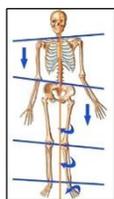
Our society seems to put a high value on individuals being “independent”. To a large extent this is a myth. Who is truly independent? I am dependent on my staff, I am dependent on my wife, I am dependent on my mechanic, and the list goes on. Are we not actually all socially interdependent? When we look at the issue of caregivers from this perspective, we see an increase in social interdependence rather than a decrease in independence (which never really exist in the first place) . . .

Perhaps this is food for thought.



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Do you have a question for Dr. DeMayo?

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