

CASEINPOINT

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Coordinating Care, Changing Lives

HOLDING HANDS, CHANGING LIVES

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“One day you’re walking and doing everything for yourself, and in a flash all of that changes. You’re in a wheelchair and you have somebody helping you. It gets to your mind. You start to have a low opinion of yourself.”

So says Tracey, a 41-year-old woman with multiple sclerosis (MS) describing how the neurological disorder has affected her life.

Case managers face a variety of issues when working with MS clients, whether in an independent living setting or in a nursing home. They range from emotional concerns like feelings of low self-esteem, fear, anger, depression and frustration to dealing with physical issues like balance and mobility, fatigue and memory loss.

The majority of people with MS are initially diagnosed in the prime of life — their 30s, 40s and 50s. Before their diagnosis, they were living their lives, raising their children, caring for their families, going to work and handling everything themselves. With the onset of MS, everyday stresses became intensified because of worsening symptoms and loss of function. Spouses or friends may abandon them, adding further stress and isolation.

Inglis Foundation, a specialized facility with more than 130 years of experience helping people with physical disabilities, treats a large number of MS patients. Nearly 40 percent of its residents are diagnosed with the disorder.



The Role
of the Case
Manager
Working
with Clients
with Multiple
Sclerosis

MULTIPLE SCLEROSIS

Today, Inglis also works with people with disabilities living on their own in the community. The services needed to maintain their independence are fragmented over many providers and funding sources. Coordinating these services can be bafflingly complex.

The Inglis Care Management Program was created to provide and assist its care managers with needs assessment, resource identification, service coordination, referrals to agencies and providers, coaching, advocacy, and mentoring.

One of the most important questions we face is: what should case managers focus on when working with clients who have MS?

- **Respecting each client's individuality.** Each client experiences his or her symptoms differently. In addition, reactions or responses frequently change, depending on the symptoms experienced at a particular time. So, what was feasible for a client to attend to one day — making a phone call to a provider or setting up an appointment, for example — may not be on another. Understanding how MS affects functioning is important, along with the ability to exhibit patience and empathy for the client.
- **Monitoring physical issues.** In addition to the emotional and psychological effects of MS, physical symptoms — heat prostration, fatigue, memory loss, problems with speech — can also affect how a client functions. A case manager may need to schedule meetings earlier in the day when a client has more energy to participate in a discussion.
- **Maintaining open and positive communication.** This may be as simple as asking the client's opinion or offering choices rather than making decisions. Coaching them — without taking over for them — is important for maintaining a client's self-esteem.
- **Helping clients maintain their independence.** This one applies to physical surroundings as well as personal care. Finding the resources necessary for maintaining independence can be overwhelming for a client newly diagnosed with MS or for someone who is experiencing worsening symptoms. A case

manager can be a valuable resource in finding the programs and services they need and coaching them on the steps they need to take. Both case managers and clients can gain valuable information from their local or area chapter of the National Multiple Sclerosis Society (www.nmss.org).

ONGOING CARE

While clients who are living independently face all of the above issues, they also must deal with larger concerns like finding accessible housing and appropriate health care providers.

Jeff is a 42-year-old man who was diagnosed with MS two years ago. The rapid onset of his symptoms meant he was no longer able to work. Recently divorced with four young children, he had to find a rental home that was both accessible and affordable. This proved exceedingly difficult.

While the home he rents is not accessible, his landlord was willing to allow him to install a stair lift so he can reach the second floor. His case manager, Jennifer Kanthor, helped him gain access to Pennsylvania Medicaid waiver services, which paid for the Stair-Glide® and its installation. Unfortunately, he stays inside most of the time because there is still no ramp outside.

Kanthor, a licensed social worker, reports that everything is a struggle for Jeff, from the changes in his living situation to obtaining food stamps and arranging insurance coverage. He suffers from memory lapses and intense pain. Kanthor has coached him on finding a neurologist who specializes in MS so he feels more comfortable discussing his condition.

Existing family stresses may become even greater when one member is dealing with MS. Valerie is a 30-year-old client with rapidly progressing MS. She lives with her mother and sister and has a daughter with speech and learning disabilities. Her mother was overextended, trying to attend to both Valerie's and her granddaughter's care needs. Valerie's case manager worked with her to get attendant care in the home and relieve some of the daily stress.

In addition, as Valerie lost the ability to move

around on her own, the family home became less accessible for her. Her most immediate needs were a stair lift and an outside entrance ramp. The process of finding a contractor, getting the necessary approvals and all the other steps to complete the project were frustrating for Valerie.

Says case manager Jacqueline Smith, MHA, CMC: "Getting these home modifications couldn't happen fast enough for Valerie. I try to get my clients as involved as possible in the process so they understand why delays happen."

Dawn Sutcliffe has been a case manager in the Inglis House Social Services Department since 2006. Nearly two-thirds of the 80 residents she works with have MS. "You have to get to know each resident as an individual," she says. "Many residents led exciting, fulfilling lives before they were diagnosed with MS. They were teachers, nurses, attorneys, scientists. I would love to have known them in their previous lives! You can't fully understand them unless you get to know the real person — not the wheelchair or the disease."

She noted that once you know someone well, you can figure out the best way to approach them; some prefer unfettered honesty, some humor. Keeping communication open and having patience are also important for furthering and maintaining the relationship.

Sutcliffe has found that each resident's approach to life in a nursing home differs. Inglis House offers a much wider array of programs and activities for residents because it has a much younger population. The average age of residents is 54, and all have a physical disability that requires them to use a wheelchair.

"Some residents come here and flourish," she says. "They can't wait to get involved in the education, computer, arts and music programs. Others are sad and sit in their rooms all day watching TV."

Clients with MS can take an emotional toll on case workers. "It's hard to watch the physical deterioration brought on by MS," says Sutcliffe. She suggests that case workers be sure to take care of themselves. "I had to realize that some days you can help a resident be happier," she says, "and other days you can't." 