



**National
Multiple Sclerosis
Society**
Greater
Northwest
Chapter

ms connection

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Teaming up and speaking out— the keys to long-term care for MS

Zach Westphal, his mom Susan and their extended group of family and friends have typified “teamwork” ever since Zach, 34, found out he was living with MS nearly a decade ago.

With help from the Chapter, they have learned together about MS, how it specifically affected Zach and what they could do to support him both in his home and when he transitioned to a care facility at the end of last year.

“In Zach’s family, everyone is mobilized and energized, and their devotion is through the roof. Not everyone has this great support system,” says Sarah Winter, MSW, Zach’s care manager contracted through the Chapter.

But Susan turns the thanks back on the Chapter: “Our life improved so much when Sarah came into our family. She got us together and had brainstorming sessions with family members and others who have observed Zach’s struggles. We learned about services we didn’t know were available. And she put a lot of pressure on DSHS to do the assessment and then to act upon it. It has been incredible.”

As time went along, Susan began to develop a checklist of things that were helpful to consider when deciding whether to move Zach to a care facility:

- Is there an adequate ratio of staff to patients?
- Will he get proper help with lifting, toileting and feeding needs?
- What MS-specific training might the staff need?

- Will he be able to interact in a socially meaningful way with other residents?

Susan then shared this list with Sarah, who took the concerns back to the Chapter.

“Zach and Susan have been huge advocates for MS by talking about what they need,” Sarah says. “That kind of feedback really guides programs,

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Zach and his family enjoy a game of dominoes together.
LEFT TO RIGHT: Matt Westphal, Jessica Westphal, Nate Bell, Susan Westphal and Zach Westphal.

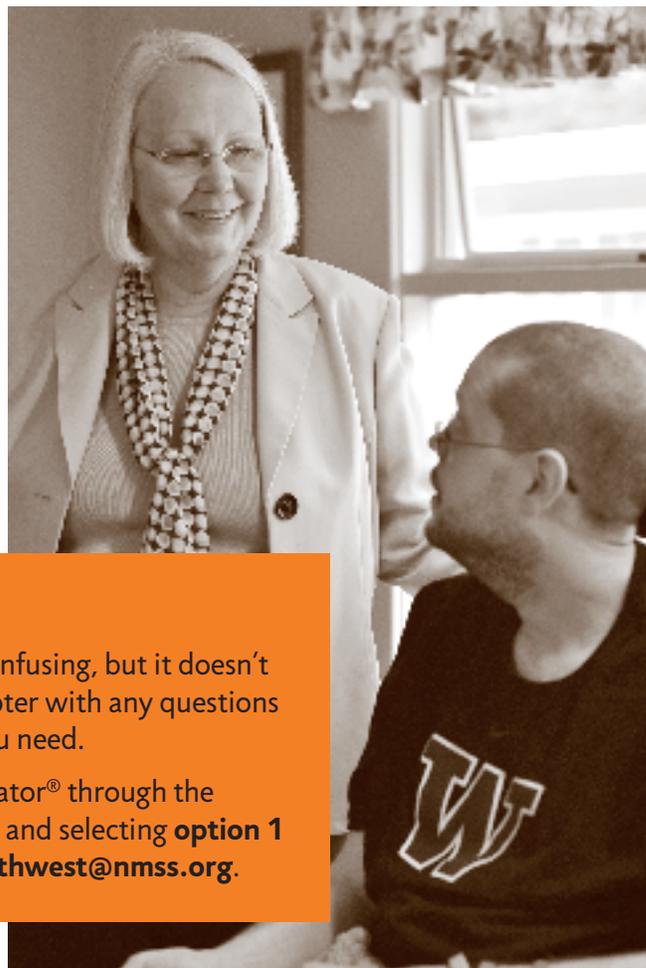
Teaming up and speaking out

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services and improvements through some pretty difficult systems.”

And that’s the key to Zach’s success story. Not only does he have family and friends who’ve chosen to become well-informed about his situation, they also share tips with the Chapter in hopes the next family’s experience with long-term care will be even better.

Or as Zach puts it: “I don’t care about people necessarily hearing my story, I care about helping people.”



We are here to help

Living with progressive MS can be overwhelming and confusing, but it doesn’t have to be. You can contact the Greater Northwest Chapter with any questions at all — even if you don’t know what type of support you need.

Start by contacting the National MS Society’s MS Navigator® through the Information Resource Center by calling **800-344-4867** and selecting **option 1** (Monday – Friday, 7 a.m. – 5 p.m. MT) or e-mail **MSnorthwest@nmss.org**.

Learn about the Society’s advocacy for long-term care on page 7.

Progressive MS: How the Society can help

If you or a family member is living with progressive MS, the Chapter has many ways to help promote independence and provide you with the tools you need to live the best and most meaningful life you can. We offer a variety of resources for education, recreation, physical and emotional wellness, and family communication. For example, the Society can help connect you with:

- Care management assistance when you’re faced with confusing information, overwhelming decisions or uncertainty about where to turn for help
- Financial assistance to support independence, safety, health and quality of life
- Financial planners
- Health professionals such as neurologists, physical and occupational therapists, and other care providers
- Emotional support services, including private counselors
- Legal assistance
- Teleconferences, educational programs and stay-at-home support groups that allow people to participate by phone
- Conversations with people who share similar life experiences for information and support — in groups or one-on-one
- Self-advocacy support to help you communicate an interest, desire, need or right
- Employment counselors
- Free online resources at **MSnorthwest.org** and the new online network for people with MS, **MSconnection.org** (see article on back page)

See ‘**We are here to help**’ above to find out how to access these services.