Support Groups: A Lifeline

Support groups are there to help address every difficult life experience you can imagine, from divorce to addiction to serious illnesses. For many, support groups can be a lifeline. And when it comes to health, that lifeline isn’t just for the person who is sick, but for those who care for them and love them.

Christopher Goetz, MD  
Neurologist

A Mixed Bag

For Mike Grauvogl, who has Parkinson’s disease (see p. 4 to learn more about Parkinson’s disease), and his wife, Linda, support groups feed separate needs.

• Clinical information. Mike wants to know everything he can about the latest medications and approaches to managing symptoms. Support groups often have expert speakers who provide this information. In fact, he and his wife first encountered Mike’s current physician Christopher Goetz, MD, a Parkinson’s specialist at Rush, at a support group.

• Perspective in terms of the illness. “In support groups, I saw how Parkinson’s affects each person differently,” Linda says. “While there are some things Mike can no longer do, it made me see that there are things that he still can do, like tinkering with his model cars.”

• Practical tips. Support groups can help you find ways to make life easier. Linda and Mike, for example, learned from another attendee about the benefits of using suspenders rather than belts, which are harder to manage for people with Parkinson’s.

Learning From Experience

As Mike and Linda discovered, there’s much to be learned from seasoned caregivers. And that’s an important component to support groups, says Kathleen Shannon, MD, a neurologist at Rush who specializes in Huntington’s disease (see p. 3). For her patients and their families, support groups are an opportunity to bring together people who have been dealing with Huntington’s for generations and those who are just beginning to understand the impact of the disease.

A Place to Let It Go

Support groups also offer a place to connect, according to James Gerhart, PhD, a psychologist in Rush’s Cancer Integrative Medicine Program. “Patients realize, ‘It’s not just me,’ and that can be very comforting,” he says.

They also provide a safe zone to process and express feelings. Hiding from feelings can be stressful and exhausting, according to Gerhart. “Support groups can relieve some of that tension,” he says.
Caregiving and Stress

Caregiving is stressful and can lead to serious mental health issues. How can caregivers deal with emotional stress? How can you tell the difference between being down or truly depressed? Rush Generations asked Kate Krajci, LCSW, a social worker with Rush Health and Aging, to provide some insights.

Roughly one third of adults in America are caregivers — responsible for helping someone with day-to-day activities and medical care. Most spend about 20 hours per week assisting relatives or friends who are 50 years or older. Caregivers are responsible for a variety of tasks and roles, many of which are physically or emotionally demanding.

Dealing With Emotional Stress
Caregivers often have to navigate changes in their relationship with the person they are helping, conflicts with others who are invested in the person's well-being and a variety of conflicting demands on their time.

So it’s not surprising that research shows that 30 percent of caregivers feel emotional stress as a result of caregiving.

To combat emotional stress, caregivers should make sure to take care of themselves — by getting enough rest, exercising and doing activities they enjoy.

It Can All Build Up
When stress adds up, it can lead to depression, which roughly half of caregivers experience. A serious condition that must be treated, depression may cause the following symptoms:

- Depressed mood
- Loss of interest or pleasure in typically enjoyed activities
- Changes in appetite, weight or sleep
- Frequent low energy, difficulty concentrating or making decisions
- Feeling worthless or guilty
- Thinking about death or suicide

If you experience — or see another caregiver experiencing — a combination of the above symptoms for two weeks or longer, seek help from a physician or counselor.

When you’re not healthy, you can’t help other people in your life. Taking care of your emotional health will enable you to be the kind of caregiver you want and need to be.
Huntington’s Disease Research

A rare neurological condition, Huntington’s disease is the birthright that no one wants, but that some families must face. When one parent carries the Huntington’s gene, a child has a 50 percent chance of developing this disease, which is both debilitating and deadly.

After years of hard work, researchers are making advances in Huntington’s disease, according to Kathleen Shannon, MD, a neurologist at Rush who specializes in Huntington’s disease. As with any research, though, progress comes in stages.

A Big Discovery
First described as a hereditary disorder way back in 1872, researchers didn’t identify a genetic marker (an alteration in DNA) for the disease until 1983. This discovery paved the way for genetic testing.

“While many family members at risk for Huntington’s choose not to be tested, some do,” Shannon says. “Depending on the findings, this can be liberating or provide information that helps with making decisions about the future, whether it’s about having children or continuing with jobs.”

In 1993 came an even bigger breakthrough: Researchers isolated the gene itself, finding that a pattern of DNA repeats itself more often in people with Huntington’s. Based on this information, researchers in the laboratory developed animal models to help them better understand the progression of the disease and the effects of investigational treatments.

From Lab to Clinic
One such treatment has shown promise in the lab: a gene-blocking drug designed to stop DNA from sending signals to create the proteins that lead to Huntington’s disease. Shannon is hopeful that this treatment will make its way to patients via clinical trials in the next year or so.

Current Clinical Research
In a clinical trial currently recruiting participants, Shannon and researchers around the country are assessing the effectiveness of high doses of creatine in slowing down the worsening of Huntington’s symptoms.

In another study, Shannon and her peers are collecting blood and DNA samples to determine why some people affected by Huntington’s get sick later than others. This answer could lead to treatments that delay the progression of disease and give more patients more time to enjoy their lives.

To find out more about the Huntington’s trial for which Shannon is recruiting participants, visit rsh.md/huntingtons-research.

If you’ve known someone with Huntington’s disease or you’ve been affected by it yourself, you understand how physically and emotionally grueling it can be, for individuals as well as for families.

Symptoms of Huntington’s disease typically appear in one’s mid-30s and 40s, although they can surface earlier or even later in life. On average, patients live 15 to 20 years after the onset of symptoms. Initial symptoms often include behavioral changes, such as moodiness and irritability, followed by unusual movements (e.g., sudden jerking, unsteady walking). Problems with memory, speech and even swallowing also occur.
Dorothy McKinney has been a Rush Generations member from the beginning and will help us celebrate our 10th anniversary. Dorothy is a retired Chicago Public Schools teacher who taught English as a second language.

Dorothy embraces volunteerism and works in the 2nd Ward Alderman’s office, distributing health and safety information to older adults.

Since joining Rush Generations, Dorothy has taken yoga, tai chi, the Take Charge of Your Health workshop and the Matter of Balance Fall Prevention class. Dorothy comes regularly to the Rush Generations monthly health education lectures and is also an active and vocal Rush Generations ambassador who participates on the Rush Health and Aging Community Advisory Committee.

Dorothy boasts that Rush keeps her strong. She was honored as the Rush Generations Member of the Year in 2013 and has received special recognition from the City of Chicago for her many years of volunteerism.

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### THINGS TO KNOW ABOUT PARKINSON’S DISEASE

1. Common symptoms of Parkinson’s include tremor and slowness, apathy, depression, sleep problems, memory problems and gait freezing.

2. Although there is currently no medicine that can stop or slow the progression of Parkinson’s disease, studies have shown that it progresses very slowly in most patients.

3. Medications are available to treat many Parkinson’s symptoms.

4. In addition to taking medications, there are several things patients can do to improve their outcomes. Regular exercise, for example, helps maintain physical function. Staying active and social helps with memory, depression, anxiety and other psychological issues.

5. With proper care, many patients can live with Parkinson’s disease for 10 to 25 years before they develop serious complications.