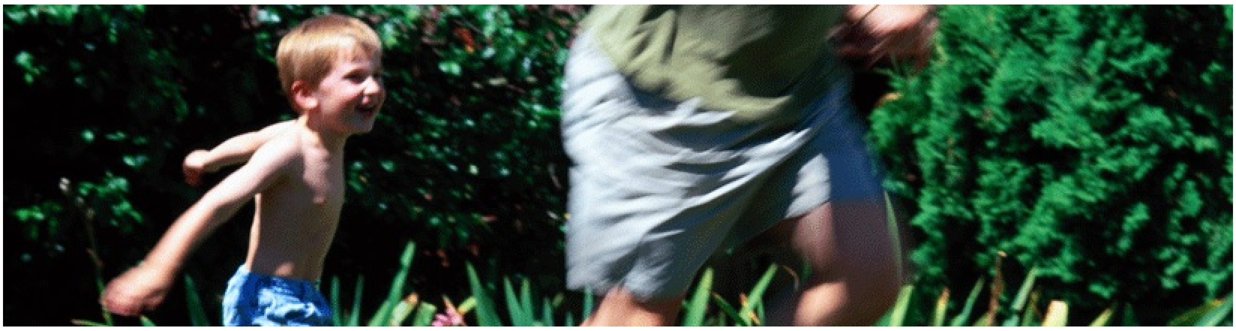

In This Issue of the Patient Voice

September 2017

September is Chronic Pain Awareness Month and the NAF invites you to share your personal stories, experiences, questions, news and tips, with our readers and the neuropathy community. Your story may be published in an upcoming Patient Voice newsletter! Simply email us at info@neuropathyaction.org.

New DPN Resource

NAF Launches DPN Awareness Poster in English and Spanish

Earlier this year the NAF released the results of a national Diabetic Peripheral Neuropathy (DPN) patient Quality of Life (QOL) survey. Out of 978 total survey responses the majority of patients reported that they were misdiagnosed multiple times before they were accurately diagnosed with DPN (59%). More than 52% reported that it took more than a year to be accurately diagnosed. Of these individuals, more than 49% reported that it took over two years to be accurately diagnosed. The majority of survey respondents reported that they currently experience nerve pain (64%). Given these results the NAF is now launching a poster in both English and Spanish to be hung in providers' offices in hopes of bringing awareness to this disease. Our goal is to bring additional awareness to DPN and help the general public better recognize the symptoms and warning signs of DPN. We also hope the flyer sheds light on the importance for patients to have meaningful conversations with their healthcare providers about how to better recognize and manage DPN symptoms. The poster can be viewed in English and Spanish below.

English Version

Spanish Version

Developments on Breast Cancer and Neuropathy

Neuropathy Finally Gets Some Notice

By Kathy Latour, cure
I can't believe it. I can't believe it.

For years, I have watched new cancer studies, hoping to see one on

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Patients Facing Denials or Delays

Denied Health Insurance or A Medication You Need? Don't Fight It Alone!

The California Chronic Care Coalition (CCCC) recently launched the My Patient Rights (MPR) which is a website inspired by actual patients who have experienced denials, delays, high out-of-pocket costs, out-of-network charges and other barriers to quality, affordable health care from their health plans. These patients want to make it easier for you to understand how to resolve issues with your health plan, reach the applicable government agencies, file a complaint and get the health care you deserve. If your health plan has denied any health care services or prescriptions - or if you have experienced any other barriers with your health plan that leave you dissatisfied, MPR can help you resolve these problems. MPR wants to help people who are dissatisfied with the decisions made by their health plan. MPR's goal is to make it easier for patients to reach the appropriate state agency to obtain information quickly, file a complaint if necessary, and get the medical treatment they need.

Through MPR patients in 17 states, soon to be more, can use MyPatientRights.org to find links to their health plan's complaint forms, where to go to file a complaint with their state's regulatory agency, and ultimately share their story. By sharing their story, or that of a loved one, they help highlight recurring health care barriers that place other patients at risk. They help bring awareness to particular problems so other patients won't have to suffer the same denials, delays, and anxiety. MPR places a high priority on ensuring that personal healthcare information remains confidential. Patients don't have to include specific health-related details in their story, but instead, explain how denials or delays to healthcare treatments or services have affected their health. For more information please contact MPR at www.MyPatientRights.org.

Learn To Thrive As a Caregiver

Caregiver Overload

By Ken Taylor, PPM Advisory Board, VP of International Pain Foundation

As Fall kicks in to season, people are feeling overwhelmed and the to do list is piled up. As a caregiver, this is the time to reevaluate goals and timelines. Being a caregiver is peripheral neuropathy for women like me who were treated for early-stage breast cancer.

About six years after my treatment ended, my feet began to swell and were so painful that I was going down the list of painkillers trying to get relief. I finally gave up trying to figure it out and cure it, and have been on methadone since around 2000.

It is true that when your feet hurt, the world is just not the same.

I now wear orthotic shoes that help, and with the painkillers, I can get around as long as it does not include long walks or long days on my feet. My feet are double-wide and finding shoes has been a nightmare. I have tried electric shock, different kinds of drugs and every other conceivable cure to no avail. My feet hurt all the time and a few years after my feet began to hurt, I noticed I could not clap anymore.

I wrote a story on neuropathy for CURE a number of years ago, looking at which drugs cause neuropathy and all possible drugs and natural cures. Acupuncture does help with the pain, but has to be repeated frequently and at around $100 a pop, is just not sustainable.

I also now cannot clap because my hands hurt so much.

Part of my frustration has been the lack of information about the whys and hows from the cancer community. There has been a slow recognition that some specific new drugs cause neuropathy, but it seems like no research has looked at those of us treated many years ago who did not get those drugs.

Finally, not just one but two studies have shown up. They don't say much except that we need to know more about neuropathy for women treated for early stage breast cancer. We

made up of many tasks not only for the patient you are caring for but also making sure you and the rest of the family are taken care of as well. Be sure to ask for help when needed so that you do not get burned out. Asking for help is a sign of strength as a caregiver. When you ask for help be sure to give tasks that are clear, fully explained, and have an end. Many times, overload can kick in with those volunteering to help the caregiver but if they know what their ask is and know that it is possible to complete, chances are they are more willing to complete it.

As you delegate tasks be sure to break them down into doable tasks. Remember how it can overwhelming for you to take on the world in this situation and realize that it is the same challenge for others. It's also important to make time for yourself. Remember, we all deserve time to do low key, non-stress activities that are good for us. When you face an overwhelming challenge write it down, decide how it can be broken up into parts and it may help to share them with someone. Not to complain, but to brainstorm on how to overcome the challenges as a team. As a caregiver, asking for help means you may have a better grasp of the situation. Being proactive with problem solving, well, it is a lot to take on.

What's a good response to the statement, "Call me if you need me?" Even though we caregivers are drowning in responsibility or are really confused about what the next step ought to be, we often respond "no thanks" when help is offered. Asking for and accepting help is a complex issue. Obviously, you first need to admit that having some help will make a real difference as well. Then you need to define what help you need. Which tasks or chores would be the easiest to ask others to do? Which do you really want to do yourself? And which, if any, can you afford to pay others to do? If this just sounds like more work, know that it doesn't have to be an overwhelming task but rather just a way to organize the thoughts and information you already have.

Recognize that care giving, like any job, is made up of lots of individual tasks, not all of which are of the same importance. Some tasks take a few minutes; some may take many hours. Some tasks are easy; others require some skill and fortitude. The challenge is to know the difference.

One task this time of year is sending our kids back to school. Considering that the kids need to get to/from school, extracurricular activities, picking up school supplies, making school lunches can be a lot to keep track of daily. Setting up carpools so that it's not one of your daily responsibilities and the tasks can be accomplished by a team of parents is a good way to free up even more time for yourself and those who do need extra assistance. Sharing tasks can help give you some of your time back to start on the pile of thing to do as a caregiver.

don't know much about it and there is no treatment, but they confirm I am not crazy. They confirm that other women treated for early stage breast cancer have neuropathy. And that it gets worse over time.

I know that some women have peripheral neuropathy as a late effect, or something that shows up after treatment ends. I have been willing to concede that I am an anomaly, and that my neuropathy is not normal if someone would tell me what to do about it.

I would love to be able to wear decent shoes and clap at the end of a performance. I'd appreciate anything that works just a little. In addition, it would be great if someone could tell me how to keep it from getting worse.

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Forward To A Friend

It is also Chronic Pain Awareness month in September, getting a little advocacy accomplished is also important but can be done in some simple ways. Talking to those around you about your loved one's disease and challenges. Volunteering to speak to your children's class or helping your child's school put a project together to raise awareness. If those in the community know the challenges you are facing, they will also be able to help more.

Don't know where to start yet? Group your tasks into categories such as personal care tasks for your loved one, transportation, household chores, school projects. You can group your tasks into only a few broad categories, or many specific ones. There's no right or wrong way. It's all a matter of personal preference when it comes to organizing.

Type out your care-giving worries. Where will we get the money to pay for her medications? Who will care for her if I get sick? Where can I find a daycare facility that provides transportation? Seeing them in black-and-white helps diffuse some of their emotion. It also allows you to think more rationally about your concerns and understand how getting help with some of your tasks might lessen the stress. Share your lists with someone you trust before you reach out for help-a friend, therapist or clergyman, perhaps.

Get comfortable through practice with idea of talking about your need for assistance and hopefully get some encouragement and good ideas in the process. Ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, especially if you are looking for hands-on assistance or something that requires someone doing you a favor. Don't get discouraged if you get rejected at first. It sometimes takes perseverance.

Remember that the effort is worth it because the goal is better care for your loved one and yourself. Wishing you each a productive, organized, and fun filled fall season!

Reprint: Pain Pathways Magazine Fall 2017, Ken Taylor, International Pain Foundation

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Stay Connected to the Neuropathy Action Foundation

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