

Helping Patients Understand, Report and Manage Chemotherapy-induced Peripheral Neuropathy

For many patients, chemotherapy-induced peripheral neuropathy (CIPN) is one of the least expected and most upsetting side effects of cancer treatment. Yet patients often overlook or neglect to report symptoms because they may not realize they are caused by chemotherapy. The more effectively you can help your patients recognize them, the sooner you can properly evaluate them and together make informed decisions about the best course of care. The following tips provide guidance on helping patients recognize symptoms, understand the importance of reporting them and balance symptom management, treatment and long-term quality of life. Talking points are also provided to aid in communication with your patients. The brochure “[5 Facts You Should Know About Chemotherapy-induced Peripheral Neuropathy](#)” can be used to discuss this issue with your patients.

TIPS

Why neuropathy can be challenging to diagnose

- Neuropathy symptoms present in many different ways and individual patients may describe what they’re feeling very differently, or they may struggle to explain feelings that are “funny,” “strange” or “weird.”
- Patients are generally less familiar with neuropathy than other side effects and simply may not understand what to be aware of or what the symptoms may feel like. Since neuropathy is harder to identify than hair loss or nausea, for example, patients may not realize they are feeling symptoms that they should report.
- Patients concerned about having to reduce or stop treatment may choose not to report symptoms.
- Because neuropathy is more likely to show up several weeks or months into treatment, patients may not remember what you and your care team discussed about it at the onset of treatment.
- Since there is no easy way to test for neuropathy, you and your care team must rely on – and encourage – patient reporting of symptoms.

When to talk about neuropathy

- Talk to patients early and often about neuropathy, especially if their particular medication regimen carries a high risk.
- Discuss neuropathy before treatment begins, at the same time you discuss the benefits and risks of chemotherapy. Even though neuropathy doesn’t usually occur until later in treatment, patients should be educated about it right away.
- Do not wait to discuss neuropathy until patients are sitting in the infusion chair preparing for their first treatment. Anxiety levels are high at this time, making it difficult to retain new information.
- Once treatment begins, continue to ask patients at every visit if they’re experiencing any neuropathy symptoms as well as observe any behavior that may indicate neuropathy.

How to evaluate the severity of neuropathy symptoms and their impact on quality of life

- It can be challenging for care teams to understand the extent of functional impairment patients who experience neuropathy may have.
- It is important to ask about work, hobbies and other activities important to an individual patient’s quality of life when assessing the impact of neuropathy symptoms. This information can affect patient willingness or unwillingness to tolerate particular symptoms.
- Clinician-administered grading scales such as the National Cancer Institute Common Terminology Criteria for Adverse Events (NCI-CTCAE) Neuropathy Sensory subscale, Total Neuropathy Score and laboratory-based measures such as nerve conduction studies tend to underreport the impact of neuropathy on patients.
- There is no single gold standard for measuring the severity of symptoms, but several patient-reported outcomes (PRO) tools with neurotoxicity-specific measures are available to help you more accurately assess neuropathy symptoms and detect meaningful differences in their impact on quality of life between treatments.



The instruments range from brief assessments with six items to extensive questionnaires with 32 items. Most include questions about activity limitations and some also ask about psychosocial impact.

TALKING POINTS

The bullet points in this section are for your consideration as talking points to use when explaining CIPN to patients.

Define chemotherapy-induced peripheral neuropathy: Although some patients, particularly older ones, may be aware of neuropathy because of another condition such as diabetes, many will not be familiar with it.

- Peripheral neuropathy can be a side effect of cancer treatment medications.
- Symptoms vary widely but are most often sensory-related, primarily affecting the hands, arms, feet and legs.
- Symptoms tend to be the same on both sides of the body. For example, they affect both hands or both legs. They tend to start in your toes and move up your ankles and legs like stockings or start in your fingers and move up your hands and arms like gloves.
- Your symptoms may be mild and have little effect on daily life. Or, they may be more severe and interfere with your daily activities.
- Your symptoms may be temporary and end with your treatment. However, sometimes symptoms may be permanent.

Be specific about the many different ways patients describe symptoms: Let your patients know that individuals who have experienced neuropathy describe it many different ways. Encourage them to tell you about anything unusual or new, rather than trying to decide for themselves whether symptoms are neuropathy-related.

- Many, but not all, symptoms fall into the following “buckets:”
 - Unusual sensations. For example, tingling, numbness, skin crawling, itching, pins and needles, ringing in ears, feels like when you’re in cold weather too long.
 - Pain. It may be shooting, burning, sharp, stabbing or like an electric shock. It may be a cramping discomfort.
 - Sensitivity changes. You may be extremely sensitive to cold or heat on your fingertips or the balls of your feet, find you can’t stand having your hand rubbed, feel your feet are sensitive to the bed sheets, feel like you’re wearing gloves or stockings even if your skin is bare, or you may have a reduced ability to sense pressure.

- Other difficulties. These include loss of balance, shuffling, shaking or feeling like you're walking with a pebble in your shoe. Or it may be having trouble feeling the shape of small objects, putting on the backs of earrings or zipping pants.
- Even if you can't be more specific than "I have a weird feeling in my fingers and toes" or "my feet feel stiff," please let us know. Believe it or not, that information is helpful.

Look for signs that your patients are experiencing neuropathy, even if they don't report it. Watch for patients who:

- Have difficulty walking
- Struggle to button or unbutton a shirt
- Have trouble holding a pen
- Wear sandals in winter, indicating regular shoes may hurt their feet

Communicate the risk of neuropathy: Emphasize that neuropathy is a relatively common side effect of many medications even though not everyone experiences it.

- Whether or not you experience neuropathy depends on several factors, including the type of medication, the dosage and how long you take it.
- Your age, family history and medical conditions such as diabetes or HIV infection can also affect how likely you are to experience neuropathy and how severe it is likely to be.
- Neuropathy does not usually happen with your first dose of medication but it may occur later in your treatment.

Make sure patients know what to do if they develop symptoms. It is important for them to understand why it's critical to tell the care team so together you can discuss what can be done to improve or manage symptoms, as well as prevent them from becoming more severe or irreversible.

- There's no need to go to the emergency room. But let us know at your next regular appointment or before you start your next scheduled chemo dose.
- The sooner we recognize your symptoms and address them, the better your chance of avoiding long-term problems.
- We will carefully evaluate your symptoms and their impact on your quality of life. It's important for us to know if they affect your ability to work, enjoy hobbies or participate in other activities.
- Together, we will decide what steps to take next. We may lower your dose or give you the same dose over a longer period of infusion time. We may take a temporary break from treatment until your symptoms improve.
- It is very common to modify treatment plans or skip treatment. This is done for many different reasons – not just neuropathy symptoms. Doing this may not substantially reduce the long-term effectiveness of your treatment.

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Once neuropathy symptoms occur, discuss the options for managing and relieving them. Reassure patients that there are ways to manage the side effects and still continue treatment.

- Duloxetine, an antidepressant, has been proven to help relieve symptoms.
- There are some other drugs which may provide relief, even though the benefits have not yet been proven. These include tricyclic antidepressants, gabapentin and a topical gel.
- Many patients also find relief from a variety of complementary or alternative treatments, which have not yet been proven. You may want to try Vitamin B, ginseng, dietary amino acid supplements, fish oil, acupuncture, yoga and/or neurostimulation techniques.
- There are also some precautions you should take so you don't hurt yourself. These include:
 - Be careful when handling knives, scissors, and other sharp objects.
 - To avoid falling, walk slowly, hold onto handrails and put no-slip bath mats in your tub or shower. Remove area rugs or cords you could trip over. Use a cane or other device to steady yourself when you walk.
 - Wear tennis shoes or other footwear with rubber soles.
 - To avoid being burned when checking water temperature, use a thermometer and gloves instead of your bare hand. If possible, lower the temperature setting on your hot water heater.
 - Allow yourself time to rest.

Suggest participating in a clinical trial studying neuropathy. Clinical trials currently underway are listed at www.clinicaltrials.gov. If clinical trials are available at your site, ask the research nurse to contact the patient to discuss participating.

- Many research trials are underway to identify ways to prevent and treat neuropathy.
- By participating in a clinical trial, you'll help us learn more about how to treat and improve neuropathy symptoms.
- Offer to provide additional information about specific trials.

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