

This factsheet has been written to support bowel cancer patients who are about to embark on a course of oxaliplatin, a common chemotherapy drug, which can cause temporary, and in some cases, more long-lasting side-effects such as tingling or numbness in the hands and feet. It is important that you work together with your hospital team to manage these side-effects and prevent problems in the future.

Oxaliplatin (Eloxatin) is a platinum-compound chemotherapy drug given to bowel cancer patients routinely to prevent recurrence or when their cancer has spread, locally into the lymph nodes or into other organs. It is usually given in combination with other drugs, for example:

- with 5FU (FOLFOX)
- with capecitabine (XELOX or CaPOX)
- with 5FU and irinotecan (FOLFOXIRI)

Oxaliplatin is given as a slow, intravenous infusion which is repeated at regular intervals, every two or three weeks, depending on the treatment you have been prescribed. Side-effects from oxaliplatin may include a sore mouth, feeling sick, diarrhoea and tiredness.

Peripheral neuropathy is another, potentially significant, side-effect of oxaliplatin, which causes altered sensations in your hands and/or feet. This is because this drug can affect the nerve endings; the longer the nerve, the more likely it is to be damaged. Nerves going to the hands, feet and lower legs are some of the longest in the body. It can also affect nerve endings in the neck or throat, causing feelings of tightness in the chest and jaw and a strange feeling in your tongue.

This side-effect is called peripheral neuropathy, because it only affects the nerve ending in the extremities of your body, in particular the hands, feet and lower legs.

### Short-term (acute) neuropathy

Almost everyone who receives this chemotherapy will experience some degree of peripheral neuropathy soon after receiving the treatment. The symptoms begin during or shortly after an infusion of oxaliplatin and usually disappear a few days after treatment ends. As treatment continues symptoms may last longer or become more noticeable. They are often triggered by eating, drinking, or touching something cold or breathing cold air. Most people cope well with the short-term symptoms of peripheral neuropathy with only a few changes to their lifestyle.

Symptoms include:

#### A change in sensation

You may have a feeling of heaviness, burning or pins and needles in the affected area. Or, you may notice unusual sensations, such as a feeling of warmth or burning when touching something cold. Or, you may notice a loss of sensitivity or feeling, starting in your feet and fingertips.

#### Increased sensitivity and pain

For the first 48 hours after your treatment, you will feel much more sensitive to the cold. You may find that even light touch or pressure in the affected area feels uncomfortable or painful. You may experience a sharp or burning sensation, or it may feel like minor electric shocks. You may also feel a tingling in your face or tongue. If the pain becomes more severe, your doctor can prescribe medication to help relieve it.



### Beating Bowel Cancer

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## Difficulty with balance, walking and coordination

If your feet and/or lower legs are affected, this may make it difficult to walk, climb stairs or keep your balance. You may find that you stumble or trip more often, especially on uneven surfaces.

## Difficulty with everyday tasks

You may feel clumsy at times and less in control of your movements. If your fingers are affected, you may not be able to do 'fiddly' tasks, such as fastening buttons or tying your shoelaces.

## Things you can do to help

- After having your chemotherapy, wait in the unit for 20 minutes to warm up and have a hot drink to minimise throat spasm caused by going out into the cold.
- It is important to protect your hands and feet by keeping them warm at all times.
- Use gloves when you go out in cold weather and to avoid touching anything cold.
- Wear socks to keep your feet warm. Don't walk around barefoot at home.
- Wear a scarf or face mask if you must go outside in cold weather.
- Don't eat or drink cold or even cool foods. Eat food that is at room temperature.
- Don't sit in an air-conditioned room or car.
- Try to go for a walk every day, even for a short distance. This will prevent muscle weakness, which adds to your general lack of balance. Wear soft shoes and add padded insoles to make walking less painful.
- If it's a cold day when you have your treatment, bring gloves, a blanket, and warm socks.

## Keeping safe with peripheral neuropathy

- Always test water with part of your body not affected by neuropathy such as your elbow before you bathe, shower, or wash dishes. Turn your hot-water thermostat to a lower setting. It is easy to burn yourself if you cannot judge the temperature of water.
- Always wear gloves when working in the garden and use oven gloves in the kitchen to avoid injury. Take special care with kitchen knives and tools.
- Clear your house and garden of things you might trip on such as rugs, slippery surfaces and clutter on stairs and steps. Make sure rooms are well lit and always put a light on if you get up during the night.
- Put a skid-proof mat in the bathtub or shower cubicle, and consider using a shower stool.
- If you have problems balancing or walking, ask for a referral to a physical therapist to strengthen muscles, build balance, or prescribe a walking aid. An occupational therapist may be able to help adapt your home so daily activities are easier and safer for you.
- Check your feet every day for redness, injuries, or blisters and tell your nurse if you are concerned. It is important to avoid an infection developing.

## Long-term (cumulative) neuropathy

As your treatment with oxaliplatin continues, the amount of platinum stored in your body builds up and this increases the risk of a longer-lasting sensory neuropathy in your hands and feet. You are more at risk of these effects if you have anaemia, diabetes, or low levels of certain minerals and vitamins. Neuropathy caused by oxaliplatin usually gets better once the treatment is stopped, although some patients will experience a temporary increase in symptoms after treatment ends.

**However, if you have lingering numbness in your hands and feet between treatments, it is important to tell your medical team, because the cumulative numbness can be long lasting if the drug isn't stopped promptly.** About 10 – 20% of patients will experience these long-term side-effects, which may persist for up to twelve months after treatment finishes. For a very small percentage of people, the changes will be permanent.

### **How your hospital team can help**

It is very important to let your oncologist or nurse know if symptoms of neuropathy last beyond a few days after a chemotherapy treatment. Keep track of tingling, pins and needles, numbness, pain, or difficulty with normal activities and let your team know if they are getting worse. It is possible to reduce the dose or to change your treatment regime so that oxaliplatin is given less frequently.

There are also several treatments which can be tried to alleviate the symptoms and researchers are looking at how best to relieve this kind of pain. This might include using medications which might usually be used to treat other conditions (which you don't have) such as:

- Anti-depressant medicines, often in smaller doses than are used to treat depression
- Anti-convulsant medicines, which are used to help many types of nerve pain.

It may take more than one approach to try to find out what works best for you. Other treatments that can be tried to ease the discomfort and its effect on your life are physical therapy, relaxation therapy, guided imagery, and acupuncture. If your symptoms don't improve you may need to be referred to a pain clinic.

If the doctor thinks that you may be lacking in minerals, due to your diet, the amount of alcohol you drink or for some other reason, you may be given an infusion of calcium or magnesium to help reduce the symptoms.

**If the oxaliplatin is stopped because of worsening symptoms, you will continue to receive the capecitabine or 5FU which is given with it.** However, if your symptoms continue to get worse, your oncologist may suggest that you try another type of anti-cancer drug or decide to give you a break from chemotherapy.

### **If you are unable to work**

If long-term symptoms make it difficult for you to walk or carry out your normal daily activities, you may be entitled to financial help. If you are aged 16 to 64 you can apply for a Personal Independence Payment (PIP) to help with some of the extra costs caused by your condition. The payment is of up to £139.75 a week and you will need an assessment to work out the level of help you get. People aged 65 and over can apply for an Attendance Allowance to help with personal care.

### **Benefit Enquiries**

PIP - T: 0345 850 3322

Attendance Allowance - T: 0345 605 6055

[www.gov.uk](http://www.gov.uk)

### **Further support**

There is more information about managing the side-effects of chemotherapy and targeted therapies in these Beating Bowel Cancer publications, which can be downloaded from our website or requested as hard copies:

'Bowel Cancer Treatment - Your Pathway'  
'Advanced Bowel Cancer - Treating Metastases'  
'Living With Bowel Cancer - Eating Well'

“I am just over 6 months post chemo, oxaliplatin and 5FU. I think that it is only now that I can say that my body has recovered, I still get tired though! The longest lasting side-effect was the peripheral neuropathy in my hands and feet. I also had ‘Lhermittes sign’ - every time I put my chin down my whole body jolted from the top of my spine down towards my feet. Very frightening at first until I realised it was all part of the neuropathy. Fortunately it was the first side-effect to disappear, about two months after chemo finished, followed by my hands returning to normal, then my feet which took much longer. I am now ‘tingle free’ with just the faintest sign of numbness left, but I’m still hopeful that will go eventually.”

“The neuropathy can make you a bit unsteady and less confident on your legs. That happened to me, just after the end of FOLFOX, when the neuropathy became a lot worse. One day, I was in the bath, and I realised that I didn’t have the strength to get out. I eventually managed to roll onto my front and get up that way, but it brought home to me that I had lost a lot of leg strength. So after that, I realised that I needed to get more exercise!”

“My sister (who is an occupational therapist) gave me a little exercise to do at home, to try to improve the circulation in my feet, and get rid of some of that rogue platinum! You just use little balls, about the size and hardness of a squash ball. Put them on a smooth floor (lino, wood or laminate is good), and roll the balls between your feet and the floor for a while, using little circular motions. Try to include the toes, and make the general trend of your rolling away from the toes and towards the legs. This can also be helpful for hands, in which case, you can roll a ball with one hand, over the other hand. Concentrate especially on the fingers, and roll from the fingers towards the arms, using little circular motions. It made a big difference to me, and reduced the effects of the neuropathy no end.”

“I bought some thin, silk gloves, the sort used to line other gloves, and this really helped when using my computer keyboard.”

“I had a lot of throat tightness after cycle 2, despite keeping warm, together with neck spasms and strange swallowing. Not painful but horrid.”

“My husband only had a throat/tongue problem when he drank anything cold. He had to warm up water just to take his tablets.”