

Managing Diarrhoea with a neuroendocrine tumour

People with a neuroendocrine tumour (NET) can experience bowel changes and diarrhoea due to the tumour itself or treatments undertaken to address it. Diarrhoea means your bowel motions are urgent, watery and frequent. You may also get abdominal cramping. These changes may be for a short period of time or may be ongoing for longer periods.

Possible causes of diarrhoea in people with a NET

Tumour factors

NET hormone production – some NETs cause excessive production of hormones leading to symptoms including diarrhoea. Hormones secreted in excess by NETs that can lead to diarrhoea include serotonin (common in small bowel or lung NETs), gastrin (some small bowel or pancreatic NETs), vasoactive intestinal peptide or VIP (some pancreatic NETs), and somatostatin (some pancreatic NETs).

Carcinoid syndrome – Carcinoid syndrome is a term used to describe a group of symptoms (diarrhoea, flushing, abdominal discomfort, wheezing and fatigue) caused by excessive production of serotonin due to a NET. Serotonin is a hormone produced naturally by the body, normally used for regulation of mood and memory. People with carcinoid syndrome may experience some or all of these symptoms. To find dietary triggers it is advisable to keep a food diary and to see a dietitian.

Tumour location – NETs located in the bowel or pancreas can lead to altered gut function, malabsorption of nutrients and cause diarrhoea.

Treatment factors

Surgery – Surgery to the bowel or pancreas can cause diarrhoea due to the change in gut function, digestion and nutrient absorption after surgery. This can be short-term whilst the bowel heals and adjusts, or some people may experience ongoing change in their bowels after surgery.

Somatostatin analogue treatment – Somatostatin analogue (SSA) injections are a common treatment for NETs – Lanreotide (Somatuline Autogel) and Octreotide (Sandostatin / Sandostatin LAR). They work by reducing hormonal production of the NET and therefore improve

symptoms as a result. In some people SSAs not only reduce hormones produced by the NET, but can also reduce the effect of digestive hormones and enzymes produced naturally by the pancreas. As a result some people may experience worsening gut function and diarrhoea when taking SSAs.

Chemotherapy and radiotherapy – Diarrhoea is a common side-effect of chemotherapy and radiotherapy to the bowel.

Fat malabsorption

Diarrhoea may be a sign that you are not absorbing fat from your diet very well. This type of diarrhoea is sometimes referred to as steatorrhoea, when bowel motions appear pale, yellow, oily or float/hard to flush. Steatorrhoea may be caused by surgery, reduced pancreatic function or SSAs. If your doctor or dietitian suspects you have steatorrhoea they may suggest you take pancreatic enzymes (Creon) to help improve fat absorption. Pancreatic enzymes are only available by prescription and must be taken immediately prior to each meal.

How do I manage diarrhoea?

If you are experiencing persistent loose or watery bowel motions and discomfort when going to the toilet, speak to your doctor or nurse straight away. The cause of your diarrhoea will need to be identified first. If you are yet to start any treatment, your doctor may suggest you do so to help your symptoms. If you are on treatment for your NET, the doctor will assess whether the diarrhoea is a side-effect of this treatment or if your treatment needs adjusting. You may also be referred to a dietitian to discuss how a change in your diet may help manage your bowels.

Managing diarrhoea with diet

Before making any change to your diet ensure that the cause of your diarrhoea has been investigated by your doctor or nurse and treated appropriately. It is also good to seek consultation with a dietitian before making any dietary changes.

The following tips may help manage diarrhoea:

- Eat small, frequent meals and eat slowly.
- Avoid alcohol and high caffeine drinks, such as coffee, tea and cola.
- Avoid foods high in roughage such as grainy bread and cereals, skins and seeds on fruits and vegetables, and nuts. Try to include foods high in soluble fibre such as oats, cooked vegetables and fruit without skin.
- Bland foods such as white bread, pasta, rice, eggs, poultry and white fish may be better tolerated.
- There is no need to avoid milk or dairy while experiencing diarrhoea, unless advised by your doctor or dietitian. Dairy foods are a good source of protein. It can be beneficial to use lactose-free milk as it is more easily absorbed when you have had bowel surgery.
- You may need to adjust your fat intake, but do not do so without discussing this with your dietitian.
- Avoid spicy foods.
- Drink more water and fluids to replace any losses from diarrhoea. Rehydration products (Hydralyte, Gastrolyte) may be useful to replace water and salts lost. These products can be bought over the counter from a pharmacist or obtained on prescription from your doctor.
- If you think you may have an intolerance or allergy to a particular food, discuss this with a dietitian before making a change.
- Keep a food diary that you can take to your doctor, dietitian or nurse.

Medications

Your doctor may recommend anti-diarrhoeal medication such as loperamide (Gastro-Stop, Imodium), pancreatic enzyme capsules (Creon) or medication for bile salt malabsorption (Questran) to help treat your diarrhoea. Only take these medications if suggested by your doctor.

Telotristat is a new oral drug that has been recently approved by the Therapeutic Goods Administration in Australia, for the treatment of diarrhoea due to carcinoid syndrome that is not relieved by SSAs. It is currently not funded by the Prescription Benefit Scheme (PBS), however is available on a compassionate access scheme which your Specialist can apply for. Its action blocks the enzyme that is responsible for the production of serotonin. This drug does not act on the tumours to control their growth.

This fact sheet provides general advice to help you manage diarrhoea related to your cancer or treatment. If you require more detailed advice or are concerned about dehydration, contact your doctor, nurse or dietitian immediately.

Living with Diarrhoea

If you are experiencing ongoing diarrhoea, the skin around your anus may become sore and excoriated, due to the alkaline nature of the bowel motions, as well as frequent wiping. It can be useful to try using a barrier cream such as Sudocream, Castor Oil, Zinc or petroleum jelly (Vaseline) – this can be applied using a piece of clean toilet paper, and can be especially helpful if applied before opening your bowels (if you have time). If toilet paper feels too abrasive, try using “Chux” (or cheaper equivalents), cut into pieces and moistened with plain water – these can be discarded into the rubbish bin after use. Avoid commercial wipes if possible – these often contain alcohol and perfumes that may further irritate your skin (never flush these or other wipes, as they may clog your sewerage).

Some people find that smell can be an issue, particularly when using shared bathrooms. A product that many find helpful is “VIPoo”, which is a small spray bottle that can be squirted directly into the toilet before use, and is often quite effective.

Continence can also be a challenge, especially with very loose or watery bowel motions, and some people may feel more secure wearing a pad or protective underwear (as well as protection for bed linen). Taking a spare change of clothes (or leaving a spare set in the car) can be helpful for some. For other practical tips and information on dealing with incontinence, including financial assistance for continence products, you may find it helpful to get in touch with the Continence Foundation of Australia - www.continence.org.au or **1800 33 00 66**.

Having issues with bowels can also have a big impact on a social and emotional level. People can feel very isolated when they are worried about unpredictable bowel habits, and it can feel very embarrassing to have episodes of incontinence. It's important to get support for these very normal and common reactions, and you may find it helpful to contact Neuroendocrine Cancer Australia NET Patient Support Nurse on **1300 287 363** or NETNurse@neuroendocrine.org.au

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