

Teduglutide treatment for short bowel syndrome

Information for
patients



Abdominal Medicine
and Surgery

This leaflet contains information about teduglutide to treat short bowel syndrome

It tells you:

- How the medicine works
- How the medication is taken
- The special checks needed
- The possible side effects

Why have I been given this leaflet?

Your doctor has suggested that teduglutide is a suitable treatment option for you.

This leaflet will remind you of what your doctor has told you about this medicine. It will set out the things you will want to consider before you decide whether to start treatment with teduglutide. It will also let you know the support we will provide if you agree to start treatment.

What is teduglutide and how does it work?

Teduglutide is an altered version ('analogue') of a protein that your body naturally makes, called glucagon-like peptide 2 (GLP-2). It improves your bowel's ability to absorb fluid and nutrition from what you eat and drink.

What are the benefits?

Teduglutide can help to reduce the amount of parenteral nutrition (PN) or intravenous (IV) fluids that you need each week, with the aim that you may require fewer nights of feed or fluids.

How is teduglutide taken?

Teduglutide is a daily injection into the fat under the skin (subcutaneous). The dose will be decided by the nutrition team and is dependent on your weight.

The injection site should be rotated around the abdomen. If the abdomen cannot be used, it can be injected into the top of the thighs.

A nurse will give you, or a friend/family member, full training on how to make up the medication and how to inject it. However, you, or a friend/family member, will be expected to make up and administer the injection once you/they have been trained.

If you miss a dose and you remember the same day, it should be given as soon as possible on that day. Otherwise, you should continue giving doses at the normal time and completely omit the dose you missed. You should not give a larger dose the following day.

Storage

Teduglutide should be stored at room temperature, below 25°C. Once mixed with water for injections, it should be used immediately. Do not allow to freeze.

Do I need any special checks while on teduglutide?

Depending on your medical history you may need a CT scan prior to starting treatment.

If you still have a large bowel (colon) you will need a flexible camera test of the large bowel via the back passage (colonoscopy) before starting treatment, with further procedures at 1 and 2 years. Further procedures will probably be required every 5 years, but this will partly depend on what is found initially.

You will also need a flexible camera test of the oesophagus, stomach and start of small bowel (upper GI endoscopy) before starting teduglutide and at 1 and 2 years.

The nutrition team will review you more regularly when you start teduglutide - initially every two weeks for the first 8 weeks, then monthly for a further 4 months, at which point you can return to your usual clinic review frequency. Before each review you will be expected to make some notes to bring with you to the appointment:

A record for 2 days (48 hours) of:

- What you have drunk,
- The volume of your stoma output or how many times you have opened your bowels,
- The volume of urine passed,
- Your current weight.

We will provide a form for you to fill in.

If you can't complete the review requirements, your treatment may be stopped.

After 6 months your doctor will assess whether you are getting any benefit from teduglutide and whether you should continue treatment. This is usually dependent on whether you have had a reduction in your nights of parenteral nutrition/fluid. If there is no benefit, the treatment will be stopped.

Are there any side-effects?

Most medicines can cause side effects, but everyone reacts differently. The most common side effects of teduglutide include feeling sick, headaches, abdominal pain, and reactions around the injection site(s). A full list of known side effects can be found in the manufacturer's leaflet.

You may have some side effects or none at all. Most side effects are mild and get better without treatment being stopped. However, if they persist or become unbearable you should talk to the nutrition team if you are concerned.

Things to tell the nutrition team urgently

If any of the following apply:

- Your stoma stops working, you start vomiting or there are any concerns that your bowel has become blocked
- You get new significant swelling around your ankles
- You become breathless, particularly when you are infusing your parenteral nutrition/fluids
- You plan to stop treatment

Where should I store and how do I dispose of teduglutide?

Store teduglutide in a cool, dry place away from direct sunlight.

Always dispose of needles into a yellow 'sharps' bin provided. Once full these will be collected by the homecare company.

Where do I get my next supply?

The nutrition team will continue to prescribe the teduglutide and it will be delivered to your home.

Pregnancy and breast feeding

If you are pregnant or breast feeding, teduglutide is not recommended.

If you think you may be pregnant or planning to have a baby, please share this with the nutrition team as soon as possible.

How can I find out more?

This leaflet has been written to provide general information about teduglutide. If you have any further questions or concerns, please speak to a doctor or pharmacist from the nutrition team.

How to contact the nutrition team

Please contact us with any specific concerns you have regarding your teduglutide treatment.

Nutrition office: 0113 206 8649
(Monday - Friday 08:00 - 16:00)

Email address:

leedsth-tr.adultsifpatientenquiries@nhs.net

Please note the mailbox will be monitored between 08:00 - 16:00 Monday - Friday. For urgent queries or concerns out of these hours, please contact ward J91.

Remember if you are acutely unwell and not sure of the cause please seek advice from you GP/111. If it is an emergency, please contact 999.

Out of hours

Contact Ward J91 0113 206 8649

(Monday - Friday 16:00- 08:00, All day Saturday & Sunday & bank holidays)



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