



Dinutuximab beta for children and young people

An information guide for parents, carers and young adult patients

The purpose of this guide is to give information on the use of dinutuximab beta to parents, carers and young people undergoing treatment for cancer.

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

What is dinutuximab beta?

Dinutuximab beta, also called anti-GD2, is an antibody treatment that is designed to attack and kill neuroblastoma cells. It does this by sending a signal to the immune system to kill the cancer cells. This is why it is known as an 'immunotherapy'.

How is dinutuximab beta given?

Dinutuximab beta is given directly into a vein. This is called an 'intravenous' or 'IV' infusion. It is usually given through a central or PICC line, or implantable port. Your medical team will talk to you about which is most appropriate.

Each course of dinutuximab beta is given continuously (24 hours a day) for 7-10 days of each course. It is necessary to stay in hospital for the first course (and maybe more). This is so that monitoring can take place to see how the infusion is tolerated. If significant side effects are experienced then the rate of the infusion can be reduced or adjusted. In some cases dinutuximab beta is given for a different number of days, or as shorter infusions each day. Your medical team will discuss the treatment plan in detail with you.

In some hospitals dinutuximab beta may be available in a specially devised pump so that the infusion can be given at home. The medical team will explain how the infusion pump works and how this should be managed

at home. It is likely that the infusion pump will need to be changed at least once during each treatment course. During the infusion of dinutuximab beta, other medicines will always be given to help lessen or prevent some side effects.

Are there any side effects?

It is important to remember that everyone reacts differently to medication. Some will have very few side effects whilst others will have more. The side effects listed below will not affect everyone who is given dinutuximab beta and may vary from the first and second courses to those given later. Generally, the side effects lessen after the first one or two courses.

What are the common side effects?

Pain

Pain is a common side effect, especially on the first course. Dinutuximab beta is always given with paracetamol, gabapentin and an opioid medicine, for example morphine. These three pain killers are likely to be used with each cycle of dinutuximab beta, and may be started before the dinutuximab beta. Your medical team will explain how to take these medicines.

For the first course of dinutuximab beta, the morphine (or another opioid medicine) is usually given intravenously in hospital. As the pain becomes less

this will be changed to having the medicine orally. It is important to take the pain medication regularly, as directed by your medical team, to try to help prevent pain.

Allergic reaction

Some people may have an allergic reaction to dinutuximab beta medicine. This reaction can range from mild to severe.

Antihistamine medicine will be given before the dinutuximab beta is started. An antihistamine medicine is usually continued every day whilst having dinutuximab beta.

Signs of an allergic reaction may include skin rashes, itching, high temperature, shivering, swelling of face or mouth, redness of the face, dizziness or headache. Difficulty in breathing and chest pain may also be experienced. If you notice any of these signs, please tell your medical team immediately.

Reduced bone marrow function

Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count means there is a greater risk of infection. A low haemoglobin count indicates anaemia, which can cause more tiredness than usual. A low platelet count may cause bruising or bleeding.

Please contact your medical team if there are any signs of infection, especially a high temperature, unusual tiredness, bruising or bleeding.

Fluid retention

Dinutuximab beta can cause fluid to leak out of small blood vessels, which can cause swelling in arms, legs and other parts of the body. This can also cause a feeling of light-headedness and breathing difficulties. If there is any swelling or puffiness around the limbs, especially the ankles, or light-headedness or breathlessness, please tell your medical team.

Cough

This can be a sign of fluid building up around the lungs. If there is a cough, breathing difficulties or chest pain, tell your medical team immediately.

Headaches

If headaches develop, contact your medical team for advice. The pain medication can be altered or increased to treat this.

Nausea (feeling sick) and vomiting (being sick)

Anti-sickness medicines will be given with dinutuximab beta to reduce or prevent these symptoms. These medicines will continue throughout each treatment cycle containing dinutuximab beta. If sickness or feeling

sick continues, talk to your team as they may be able to change the anti-sickness medicines. If sickness is not controlled after going home, contact your team for further advice.

Numbness, tingling, aches and pains (peripheral neuropathy)

Dinutuximab beta may affect the nervous system. This can cause changes to sensations such as numbness, tingling, aches and pains. This is called 'peripheral neuropathy'. It may feel harder to pick the feet up and walking may be altered. Please tell your medical team if these effects happen.

If the pain or numbness is severe, a type of pain relief medication may be given to help. Your medical team may also suggest physiotherapy.

Skin changes

Dinutuximab beta can affect the skin. It can cause a rash which may be itchy. Tell your medical team if this becomes a problem. They will be able to tell you what to use on sore or red skin.

Eye problems

Eye disorders may occur as dinutuximab beta can bind to the nerve cells in the eye. If blurred or double vision, unexpected sensitivity to light, or drooping of upper eyelids occur, please tell your medical team.

Important to watch for:

If dinutuximab beta leaks into the tissues around where it is being given, it may damage the skin and tissue in this area. If there is any pain, irritation or a burning sensation, tell your medical team immediately.

Which tests/investigations may be needed?

A full blood count and blood tests for liver and kidney function are taken routinely before each treatment with dinutuximab beta. It is important that these tests are within the normal range before another cycle of dinutuximab beta is given. If the full blood count has not recovered, then the next cycle may be delayed.

These tests may be done at other times depending on the side effects experienced.

Does dinutuximab beta interact with any other medicines?

Steroid medication should be avoided for two weeks before dinutuximab beta is started and throughout treatment unless specifically prescribed by the medical team.

Some medicines can affect how well dinutuximab beta works, so always tell the doctor about any other medication being taken. Check with your doctor or pharmacist before taking any other medicines. This includes supplements, herbal and complementary medicines.

Pregnancy

If a person is sexually active while taking anti-cancer medicines or drugs, it is important to use contraception such as condoms, the pill or coil to avoid pregnancy. A pregnancy test may be needed before taking this medicine. Contraception should continue for a while after treatment finishes. Your team will advise how long contraception should continue for.

Fertility

Depending on the type, dose and combination of medicines given during your treatment, it is possible that fertility may be affected. For girls, this means that it may be harder for them to become pregnant in the future. For boys, this may mean that their sperm is less fertile, which can affect their chance of having children in the future. If you would like more information about this please discuss with your medical team.

If you have any questions about dinutuximab beta, please contact your treating hospital. This guide only gives general information.

Always discuss individual treatment with your medical team. Do not rely on this guide alone for information about treatment.

Useful information

CCLG: The Children & Young People's Cancer Association publishes a variety of free resources to order or download at www.cclg.org.uk/publications



Scan to order or download this factsheet or any other CCLG publications FREE of charge.

Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and their families.
www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk

EMC (Electronic Medicines Compendium) offers up to date, approved and regulated information for licensed medicines.
www.medicines.org.uk



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We are **CCLG: The Children & Young People's Cancer Association**, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit www.cclg.org.uk/donate or text '**CCLG**' to **70085** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.



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