



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Multiple sclerosis disease-modifying drugs – first line treatments

The following information should be read in conjunction with the patient leaflet provided by the manufacturer. However, please note that this may differ from the manufacturer's information as we are specifically referring to the use of medicines in children and young people.

This information sheet describes first line treatment of relapsing-remitting multiple sclerosis with disease modifying drugs (DMDs), how they are given and some of their possible side effects. Each person reacts differently to medicines so your child will not necessarily suffer every side effect mentioned. If you have any questions or concerns, please ask your doctor, nurse or pharmacist or telephone one of the contact numbers on this information sheet.

What are disease-modifying drugs (DMDs)?

DMDs work by interacting with the immune system and calming the inflammation that is attacking the central nervous system.

There are currently five DMDs used as first line treatments for relapsing-remitting multiple sclerosis.

- **Beta interferon 1a** (available under the trade name Avonex®) – given by injection into a muscle (intramuscular) once a week using a pre-filled syringe
- **Beta interferon 1a** (Rebif®) – given by injection under the skin (subcutaneously) three times a week using a pre-filled syringe
- **Beta interferon 1b** (Betaferon® and Extavia®) – given by injection under the skin (subcutaneously) every other day. The injection needs to be prepared by mixing the ingredients before drawing it up in a syringe
- **Glatiramer acetate** (Copaxone®) – given by injection under the skin (subcutaneously) once a day using a pre-filled syringe

There are two drugs used for second line treatment (fingolimod and natalizumab) covered in another information sheet.

The treatments do not cure MS, but can reduce the number of relapses. In adult trials, the relapses decreased by around a third, and the effect on relapses in young people with MS appears to be significantly greater than this. By decreasing the number of relapses, it appears that the long-term development of disability can also be slowed down. Some research also suggests that the earlier treatment starts, the more effective it is likely to be. These drugs may also not work for everyone, and the pros and cons of treatment need to be constantly reviewed.

Which medication should my child take?

Your doctor may ask you to look at the available choices and to choose which first line treatment would best fit with your family's and child's lifestyle. The table overleaf is there to help with this.

	Beta Interferon 1a	Beta Interferon 1a	Beta Interferon 1b	Glatiramer acetate
Trade name	Avonex®	Rebif®	Betaferon®/Extavia®	Copaxone®
How often is it given?	Once a week	3 times a week	Alternate days	Once a day
How is it injected?	Into the muscle	Under the skin	Under the skin	Under the skin
Does it come in a pre-filled syringe?	Yes	Yes	No, but easy to mix	Yes
Is there a computer device?	No	Yes	No	No
Where is it normally stored?	In fridge	At room temp for up to 30 days	At room temperature	In fridge
Common side effects	Flu-like symptoms after injecting, injection site reactions	Flu-like symptoms after injecting, injection site reactions	Flu-like symptoms after injecting, injection site reactions	Injection site reactions, post injection flushing and panic
Blood tests to monitor	Yes - monthly for first 3 months, then 3 monthly till 6 months, then 6 monthly	Yes - monthly for first 3 months, then 3 monthly till 6 months, then 6 monthly	Yes - monthly for first 3 months, then 3 monthly till 6 months, then 6 monthly	No

How are they given?

Currently, the five first line treatments are all given by injection. All the medications come with injection devices that make giving an injection much easier and the needle is almost always hidden.

In the near future, there will be oral medication available, but it will take some time before we know exactly how these should be used and how safe they are in young people. You may be asked to consider a research trial involving these medications.

Who should not take first-line DMDs?

People with any of the following should discuss using first-line DMDs with their doctor:

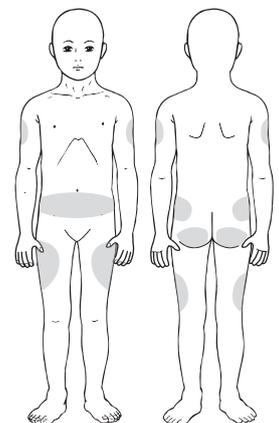
- Hypersensitivity to Beta interferon 1a or Beta interferon 1b or glatiramer acetate or any of their ingredients such as human serum albumin
- Pregnant, could be pregnant, planning to become pregnant or breastfeeding
- Depression or dark thoughts
- Severe liver disease

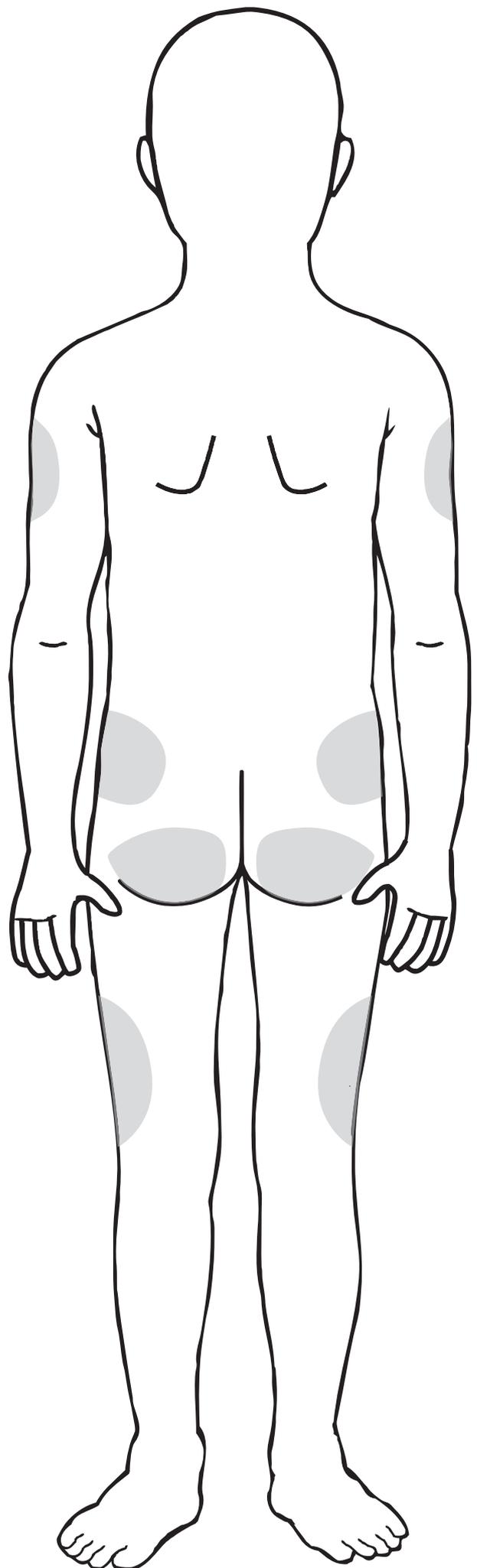
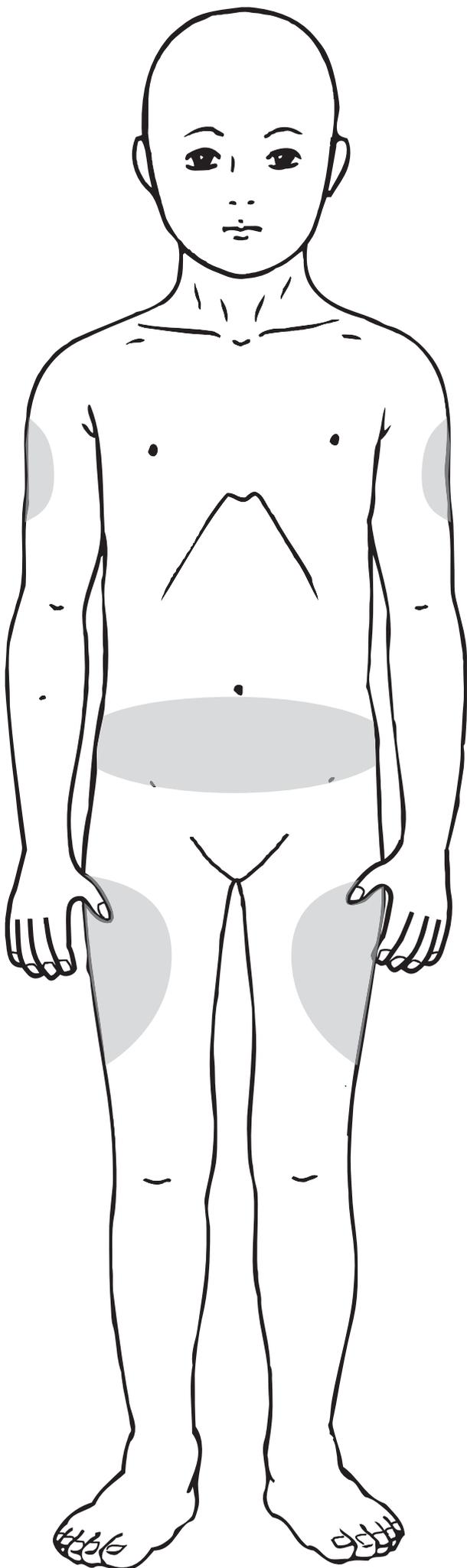
What are the side effects?

Common side effects of Beta interferon 1a and Beta interferon 1b include flu-like symptoms after having the injection and irritation at the injection site. In addition to reactions at the injection site, glatiramer acetate can cause flushing and panic after having the injection. Other more common side effects are headache, injection-site bruising, tiredness, gastrointestinal upsets and mood changes.

If these side effects cause problems, please discuss them with your doctor. It may be better for your child to switch to another of the five first-line treatments.

- **Flu-like symptoms** can be improved by giving the injection at bedtime alongside a dose of paracetamol or ibuprofen according to the instructions on the bottle.
- **Injection site reactions** can be managed by rotating the injection site. There are several areas of the body suitable for giving injections, shown on the diagram. As a general rule, suitable areas are those with a substantial amount of fat below the skin, so the thighs, buttocks and abdomen tend to be most suitable in children. As your child grows, other areas may become suitable as well, such as the upper arms but these vary from child to child. The next page of this information sheet is a site rotation chart for you to use to make which injection sites you use on which day.





Four of the five first line DMDs can cause liver and blood abnormalities. Unless your child is having glatiramer acetate injections, which does not cause these abnormalities, they will initially need to be monitored regularly with blood tests. Usually, your child will need blood tests once a month for the first three months, then every three months. Once they are stable on treatment, blood monitoring will only be needed every six months.

Your child will be seen regularly and examined, and may also have a MRI brain scan. If your child continues to have relapses, then the treatment will be changed to something more effective for your child after the appropriate discussions.

The current second line DMD options are fingolimod and natalizumab – information about these are in another information sheet.

First-line DMDs and other medicines

Some medicines can react with first-line DMDs, altering how well they work. Always check with your doctor or pharmacist before giving your child any other medicines, including herbal or complementary medicines. The following are known to react with first-line DMDs.

- Some medicines used to treat epilepsy or depression
- Medicines that affect blood cell production
- Other medicines that damp down the immune system except steroids

Important information

- Once all the approvals for treatment are in place, the drugs are delivered directly to your house. A nurse will then arrange to come to your home, and train you and/or someone from your family how to give the injection. The nurse usually gives the first injection, and they provide full support for the next few injections until you feel confident. They also give advice on other aspects of the injection, but do not usually give any MS specific advice.
- Store the drugs as directed on the packaging – some need to be stored in the fridge but others need to be stored at room temperature. If you are unclear, please ask the nurse from the homecare company.
- Store all medicines in a safe place where children cannot reach them.
- If your doctor decides to stop or change treatment, return any unused DMDs to the pharmacist. Do not flush them down the toilet or throw them away.
- If you forget to give your child a dose and it is within a few hours of when the dose was due, give it as soon as you remember. Otherwise, do not give this dose but take the next dose when it is due. Do not give a double dose.

Further information and support

The website www.MSdecisions.org.uk will specifically give you information on the different treatments available for MS and their risks and benefits

Useful numbers

- GOSH switchboard: 020 7405 9200
- Pharmacy medicines information: 020 7829 8608 Monday to Friday from 9am to 5pm