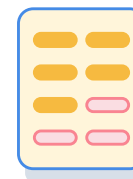


Keeping on top of treatment

Information for patients with Type 1 Gaucher disease
who have been prescribed Cerdelga

Keeping on top of treatment



▼ This medicine is subject to additional monitoring. This will allow for quick identification of new safety information. You can help by reporting any side effects you may experience. If you get any side effects talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard.

Myths and misconceptions

It can be tough with any treatment to know whether what people say is true or not. If you are not sure about anything relating to your treatment speak to your nurse, pharmacist or doctor next time you see them, or if you need to speak with them more urgently pick up the phone or send them an email. You should always consult your doctor before making any changes in treatment.

Here we explore some of the myths and misconceptions about taking medication:



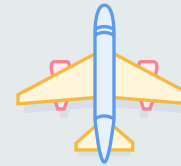
I feel better so don't need my treatment anymore

The lack of symptoms is generally a sign that the medicine is doing what it is supposed to do. By stopping you put yourself at greater risk of new symptoms. Always consult your doctor before making any changes to your treatment regime.



If I miss a dose then I can take more to make up

As before, taking more than your recommended dose can have risks. Always remember to carry on with your next dose as normal.



It is OK for me to take a break whilst I am on my holiday

Taking a break in treatment can mean it doesn't work as well at a time where you need a real break and relax. Use a bit of forward planning to take it with you, and consult your doctor before you travel to discuss possible solutions.



I will still need to go to hospital to have my infusions

Your treatment is taken as a capsule and is used to treat Gaucher Type 1 disease, instead of infusion-based therapy.



My doctor will know if it is not working

It is really important to let your specialist doctor know how you are feeling at your next appointment. They often need more than test results to really know if your treatment is a success.

Dealing with daily hassles

With anything new it can be a bit of a challenge to fit it in with home, work, family and friends. You may find that it is a bit of a hassle having to take a new treatment every day.

With a bit of forward planning you can set up good ways to take control:

- ▶ **Set a plan early on:** think about when would be a good time to take your treatment, think about what you need to make this happen and if there are any challenges that might make it more difficult. By doing this you are more likely to do it and avoid any troublesome distractions.
- ▶ **Change your surroundings:** create a new place to store your medication, make a place by your bed, and have a glass of water ready to take it.
- ▶ **Starting something new** takes time to become an established habit. Think about other techniques you have used to keep on top of the daily things you need to do.

Long-term planning

Whilst you are well established in managing your Gaucher Disease type 1, sometimes you may find that new challenges appear over time. These may mean that you find it more challenging to take your treatment or connect with your healthcare team in the future, regardless of how well things have been going.

Next time you find yourself feeling a bit tired about treatment, spend a moment to consider why this might be.

- ▶ *Is there something else going on in your life that may be a distraction, or where you need to focus your energy?*
- ▶ *Do you need to make some changes to when you take your medication?*
- ▶ *Take some time out to refocus on what your new life goals are in relation to managing your Gaucher Disease. These may be goals around work or family that you are not able to aim for.*
- ▶ *It is quite normal for patients to feel they have fallen off the track with managing their condition. Try to focus on what you have been doing well and any new changes you might need to put in place.*

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