

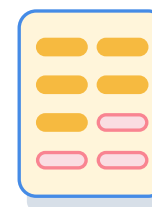
# Keeping on top of treatment

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

## Keeping on top of treatment

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▼ 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](http://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

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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 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.

## Remembering and establishing new routines

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Do you sometimes notice you can't remember to do those everyday things? If you are worried about forgetting your treatment or need some help in remembering use these simple tips to boost your memory

- ▶ Use your phone to **set a daily reminder** - remember to include a message that has meaning for you
- ▶ Spend a moment writing down what the **pros and cons** of taking your treatment are - this can help you identify why you want to take it as well as any concerns you might need to address. You can also refer back to the treatment goals you have written in this booklet
- ▶ Remember that we are **more likely to forget things** that we don't want to remember- try and work out why this might be to help find a solution
- ▶ **Practice makes perfect**- the more you set up a good routine the easier it will become to remember your medication

- ▶ **Put a reminder** somewhere useful- on the fridge, in the bathroom or close to where you keep your medication
- ▶ Ask someone you live with, or a close friend, to **help you remember**
- ▶ **Use pictures** - we can get tired of the same old words so put a picture up that motivates you to remember
- ▶ Remember **we tend to forget** when we are tired, stressed, or thinking about other things- time to invest in looking after you a bit more!

## Long-term planning

With any new treatment we tend to focus on the here and now, which is good. Sometimes we find that as time goes on we have new challenges that appear that we need to address. These can mean you may find it more difficult to take your treatment or connect with your healthcare team. To help you get back on track we have some useful steps for you to use.

**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 type 1. This 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.*

- ▶ If you think it would help to talk to someone in a similar position to you, why not contact a patient association who can give you advice and support. **You can find their contact details in the 'Talking to family and friends' booklet.**
- ▶ Finally remember that it is important to keep on taking your treatment long-term to get the most out of it.



