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Support Networks in Type 1 Gaucher Disease

This booklet is for adults with Type 1 Gaucher Disease who have been prescribed Cerdelga.

The information in this booklet is not intended to replace the Patient Information Leaflet accompanying your medication and should act as further information. If you have any questions or concerns regarding your treatment, please consult your Patient Information Leaflet, or get in touch with your specialist healthcare team.

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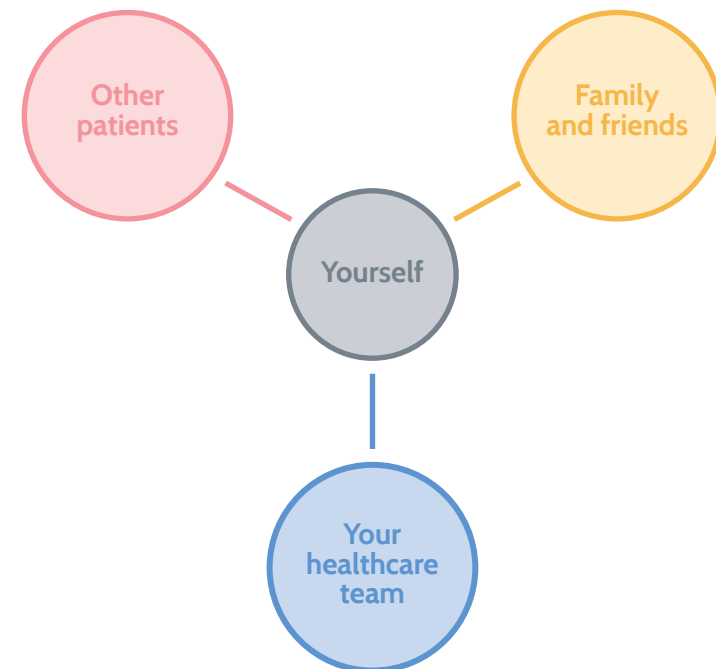
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Welcome!

This book is designed to help you get the most out of the support networks that can help you live well with Type 1 Gaucher Disease.

Learning that you can get help from others can make finding answers and getting things sorted a lot easier.

Take a look at the **Living Well with Gaucher Disease** booklet for more tips on how to get the best out of your journey with Gaucher.



What is a support network?

A support network is the group of people around you that you can turn to for help when you need it.

Friends, family and others with Gaucher Disease can all provide you with support through your ups and downs.

What kind of support can be useful?



Day-to-day support

Practical help like transport to appointments, picking up a prescription, or just supporting you around the house, can make things easier. This could even include general advice on how to get through life's trickier moments, like moving house or finding a job.



Emotional

A strong group of friends and family can be there to listen, give you a hug, and reassure you if you are feeling a bit down. Sometimes, just being around the people that you care about can cheer you up!



Medical

You will need support from your healthcare team to make sure that your treatment is working well for you. They will help you to live in the best health that you can.

Making the most out of your support network

One size doesn't fit all when you need support, and that's okay. Different people can offer different advice to you, and support you with different things. Don't expect one person to be able to manage everything.

Be proactive

To get the most out of the people around you, you still need to make an effort. Make time for the people in your support networks. Being there to support others means that they will be more likely to be there for you. It can also make you feel good!

Find support online

It's never been easier to connect with people using technology. Social media is a great place to find other people living with Type 1 Gaucher Disease – use these groups to connect with people that might better understand what you are going through.

Don't be afraid to ask for help

If you don't feel like you have people to rely on, that's okay! You can always find help from your healthcare team if you need it, it isn't something to be embarrassed about, and you shouldn't have to struggle on your own.

Your support networks: Friends and family

- **Family and friends can offer a lot of emotional and day-to-day support when you need it.** Therefore try and make a strong group of friends and keep close with your family so that you have a few people you can go to.
- **Friends and family might need some help to understand how your illness affects you.** But taking the time to talk to people about what you are struggling with can make you feel better.
- **It's also good to tell people when you are feeling okay.** Your illness doesn't have to take over – make sure you have fun by taking time out to do things you enjoy with people close to you, like going for a meal or going to see a film.

TIP: Support is generally a two-way process – this means that those that help you may also need support themselves, even if they don't ask for it! Don't forget to offer your help to others in need. Sometimes the little things, like a cup of tea and a listening ear, can go a long way.



Your support networks: Patient networks

Patient networks are a great way to connect with other people living with Type 1 Gaucher Disease. These can include social media websites like Facebook which have several communities, connecting and sharing information about life with Gaucher Disease. The more you put in to a community, the more you get out of it, so these networks can be a great opportunity to speak to someone who understands what you are going through and also give something back.



The Gauchers Association

The Gauchers Association is a charity that provides support and advice to patients and their families. They also run fundraising events that you, your family and your friends can take part in!

TIP: Meet other people with Gaucher Disease face-to-face at charity events – you might make new friends who can be a part of your support network!

Website

www.gaucher.org.uk

Telephone

01453 549231

Email

ga@gaucher.org.uk

TIP: Remember to practice online safety when you speak to others over the internet – **never give out sensitive information online**, unless you are sure it is safe to do so and they are who they say they are.

Becoming a Gaucher Disease advocate

You have more to offer than you might think

Supporting others can be rewarding, and you might have a lot to offer other individuals with Type 1 Gaucher Disease.

If you have a little free time and want to give something back to the Gaucher Disease community, you should consider becoming a Gaucher Disease **advocate**. This means helping other people with Type 1 Gaucher Disease, and you can be as involved as you'd like to be.

What is an advocate? An advocate is someone who supports a cause, so in this case it would be you supporting others with Gaucher Disease.

How can I help?

- **Join, or start, a support group**
- **Write a blog about your experiences**
- **Raise awareness of Type 1 Gaucher Disease with people you know**
- **Fundraise, or share ways for others to raise free funds, for example Gift Aid, Amazon Smile, or Give as you Live Online**
- **Offer your contact details, such as your email or phone number, so that others can come to you for advice**
- **Team up with someone else who has Type 1 Gaucher Disease and ensure they get the right support – they can do the same for you!**
- **Work with doctors who really understand Type 1 Gaucher Disease, or generally help to represent people with Type 1 Gaucher Disease and give them a voice**

Your support networks: Your healthcare team

Getting the most of your support networks includes getting the most from your healthcare team at your hospital appointments.

Your Gaucher Disease healthcare team might include a doctor and/or nurse who really understands Type 1 Gaucher Disease, and other people that are involved in parts of your treatment. They are there to check that your treatment is working for you, follow your progress, and help you to stay in your best health.

You might only have a small amount of time that you can spend with your healthcare team. Therefore making sure that you are ready for your appointments means that you can get the best from your time, and say everything you need to.

On top of any tests that they might carry out, your healthcare team might ask you some questions about your health.

It's important to answer these questions as honestly as you can, as they need you to tell them what is happening. Only then can they make the right decisions about your treatment.

What questions will my healthcare team ask at my appointment?

Possible questions:

How you have felt in general?

Have you noticed any side effects on your treatment?

How are you getting on with taking your treatment on time?

How you are coping with your Gaucher Disease symptoms, such as bone pain?

Have you missed any doses?

For more information on side effects read the **About Cerdelga** booklet and consult the patient information leaflet that comes with your medicine.

Things you might want to talk about with your healthcare team

It's best to write down the things that you might want to talk about as you think of them. This can help you remember them at your appointment. It can also be helpful to keep a Gaucher diary (for more information on this, take a look at the **Living Well with Gaucher Disease** booklet).

Things that you might want to discuss at your appointment:

- *Sports or activities you can do to stay healthy*
- *How to get more energy if you are feeling tired*
- *What you can do about side effects (if you are having any)*
- *Medicines that you might need to take in the future, and how they may affect your treatment*
- *Whether changes to your diet or lifestyle can improve any symptoms of Type 1 Gaucher Disease that you are experiencing*
- *Your risk of passing Type 1 Gaucher Disease on to your children (you can read all about this in your About Cerdelga booklet)*
- *Any mental health concerns*
- *Advice about any part of your disease or treatment that you are unsure about*

Getting ready for your appointments

On top of any tests that they might carry out, your doctor or nurse might ask you some questions about your health.

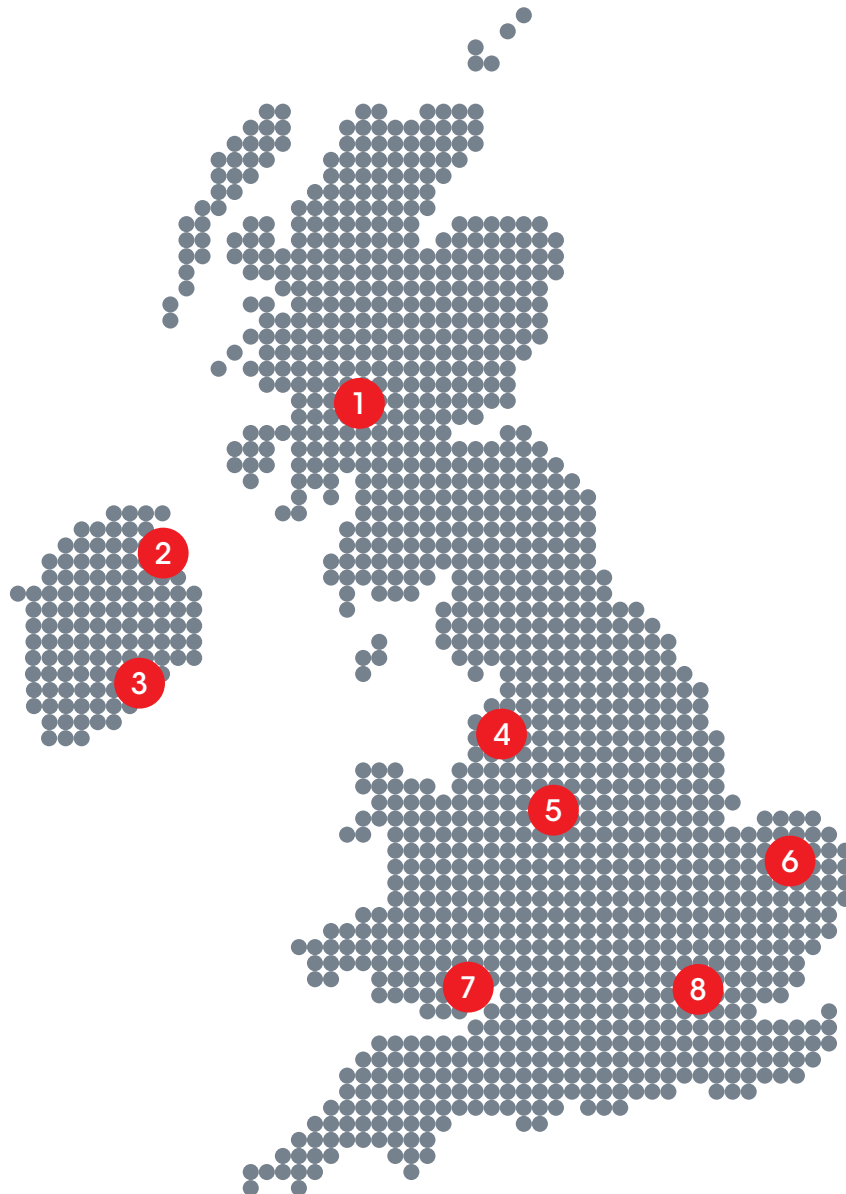
- *How you have felt in general*
- *If you've noticed any side effects on your treatment (for more information on side effects read the About Cerdelga booklet and consult the patient information leaflet that comes with your medicine)*
- *How you're getting on with taking your treatment on time*
- *How you are coping with your Gaucher Disease symptoms, such as bone pain*

I feel fine, why can't I skip my appointment?

Even if you feel well, or are very busy, it's important that you attend ALL of your appointments.

- **Your doctor needs to track your progress to pick up on any signs that something is wrong, so that they can act on it quickly.**
- **You might not have realised you're actually experiencing a side effect or new symptom.** You may be feeling small changes that you've put down to something else; it's best to let your healthcare team check you are fine.

Who to contact: UK Treatment Centres



- 1) **Glasgow:** Scottish Centre for Metabolic Diseases, Inherited Metabolic Disorders Scotland
- 2) **Belfast:** Royal Victoria Hospital for Sick Children (Genetics Dept)
Belfast: Northern Ireland Centre for Metabolic Diseases, Belfast City Hospital (Adult)
- 3) **Dublin:** National Centre for Metabolic Diseases, Children's University Hospital
- 4) **Manchester:** Willink Unit, Royal Manchester Children's Hospital (Paediatrics)
Manchester: The Mark Holland Metabolic Unit, Salford Royal NHS Foundation Trust (Adult)
- 5) **Birmingham:** Inherited Metabolic Disorders Service, Birmingham Children's Hospital (Paediatrics)
Birmingham: Department of Inherited Metabolic Disorders, University Hospital Birmingham (Adult)
- 6) **Cambridge:** Lysosomal Disorders Unit, Addenbrookes Hospital (Adult)
- 7) **Cardiff:** Welsh Centre for Metabolic Diseases, Inherited Metabolic Diseases Service, University Hospital of Wales
- 8) **London:** Lysosomal Storage Disease Unit, Great Ormond Street Paediatrics
London: Charles Dent Metabolic Unit, The National Hospital for Neurology and Neurosurgery (Adult)
London: Lysosomal Storage Disorders, The Royal Free Hospital (Adult)


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**You can refer to this booklet at any point in your treatment journey,
for information on Cerdelga.**

If you find you have more questions, there is a Patient Information Leaflet included in the packaging of your Cerdelga tablets. You can also speak to your doctor, nurse or pharmacist.

▼ This medicine is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side effects that you may get. In the UK, see www.mhra.gov.uk/yellowcard for how to report side effects. In Ireland, see www.hpra.ie for how to report side effects.