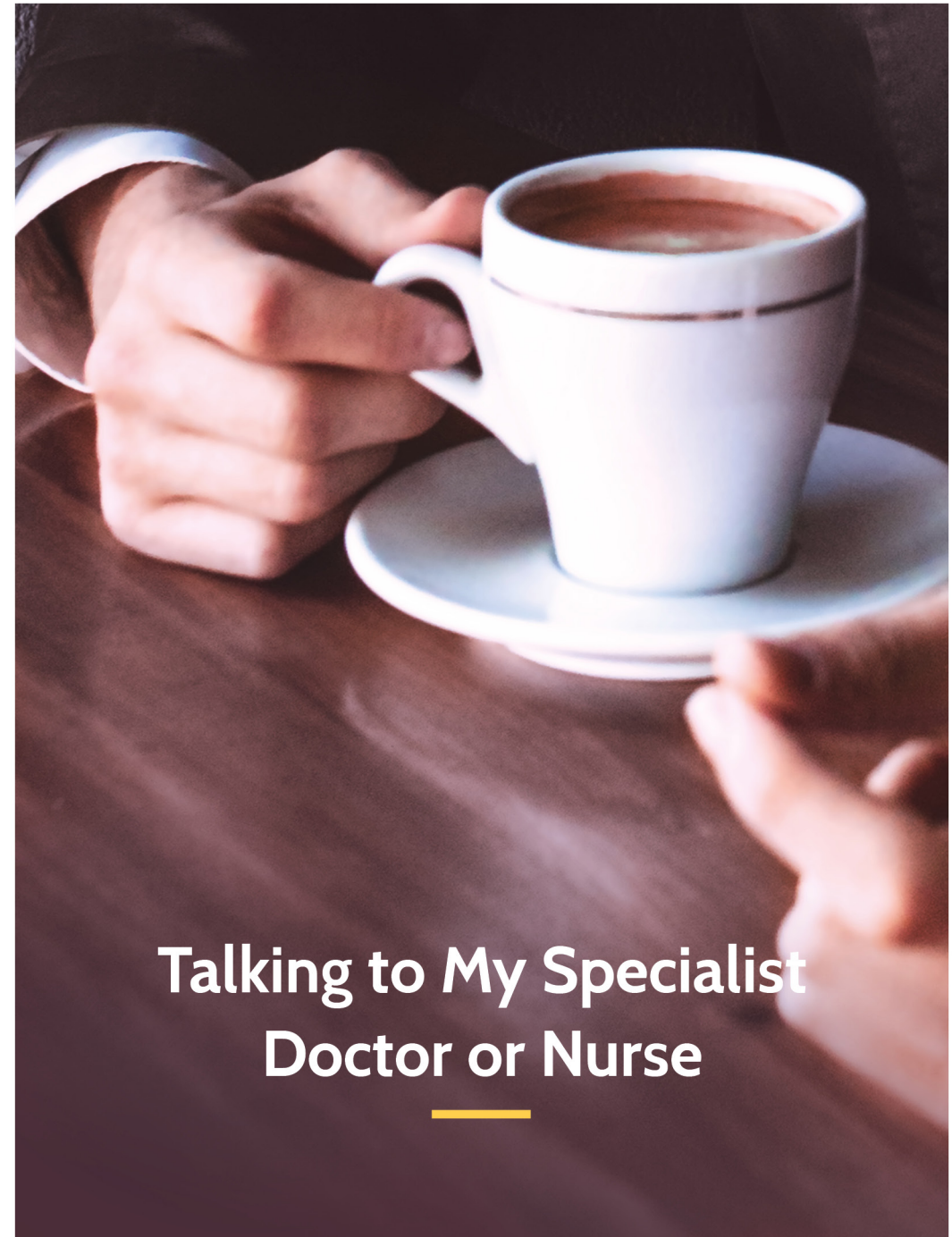


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Talking to My Specialist Doctor or Nurse

Talking to your specialist doctor or nurse

Preparing for an appointment

We know that you may have to travel a long distance for your appointment with your specialist doctor or nurse, therefore it is important you get the most from it.

This information should help you make the most from your appointment.



Why should you attend your appointment?

It can be tempting to skip appointments if you're feeling well or are too busy. There's nothing your healthcare team can do for you at the moment, so why bother?

However, it is important that you DO go to all the appointments that are made for you, for several reasons:

- ▶ **Even if you're feeling well**, it is important that your doctor tracks your progress to quickly pick up any issues should they occur. This will enable them to act quickly, and adjust your care accordingly to ensure you stay healthy in the long term, and minimise the impact of Gaucher disease type 1 on your life.
- ▶ **You may feel OK**, but when asked there may be a side effect you hadn't really noticed before, or there may be a new symptom that you have put down to something else. It's best to let a specialist doctor or nurse give you a good check-up.
- ▶ **This is your time to talk** about anything that has been bothering you, or things that are going well. You are the focus of the appointment, so unlike talking to friends and family, you can talk about ANY aspect of your Gaucher disease or your Cerdelga® ▼ (Eliglustat) treatment, in as much depth or detail as you wish, and if you have any questions you can be sure of a well-informed answer.

Informing your pharmacist

Cerdelga® cannot be taken with certain other medications.

For this reason, you must tell your pharmacist that you are taking Cerdelga® if you have a prescription for a medicine or you buy something over the counter for either your type 1 Gaucher disease or any other condition, even if totally unrelated. This is so they can check that it is safe for you to take other medicines, or offer any advice you might need.

The Cerdelga® Life pack contains a patient safety card with further information and can be given to your pharmacist.



Setting goals for your treatment

Clinical goals

The goals of Cerdelga® treatment are largely:

- ▶ To reduce the symptoms of Gaucher disease type 1
- ▶ To work as effectively as other treatment options
- ▶ To minimise side effects and make them manageable until they pass
- ▶ To give you independence, and the ability to manage your own treatment

If you feel that Cerdelga® is not achieving any of these goals, it's important to get in touch with your healthcare team to discuss ways to get you closer to a good outcome.

Starting out

Starting a new treatment for a long-term condition like Gaucher disease type 1 can be exciting and daunting at the same time. You don't know what to expect, or how well it will work for you, so it's important to be prepared and not every medication will suit every patient.

Your healthcare team will talk to you when you are prescribed Cerdelga® about:

- ▶ What it does
- ▶ How you might feel physically
- ▶ What side effects you might get

Follow-up

To see if Cerdelga® is working for you, you may have to go back for a follow-up visit. If you've switched from ERT, you might begin taking Cerdelga® from the very next day. If this is the case, you shouldn't notice a huge difference in your symptoms.

If your symptoms DO get worse, or you notice new symptoms, get in touch with your healthcare team straight away.

Personal goals to be checked by your nurses

It can be helpful, when you start on a new treatment, to take some time to think about what you would like to get out of your treatment and what your health goals might be. Having something to aim for helps you assess your progress, and it can be motivating to find that you are able to do something that you were unable to do 6 or 12 months ago.

Your goals might be practical or aspirational – so long as it's something that feels achievable and will motivate you. Ideas might include:

Practical Goals



To remember to take your medication every day



To take up a new healthy habit e.g. eating more vegetables or doing (appropriate) exercise



To keep a Gaucher diary of symptoms, side effects and experiences

Aspirational Goals



To travel abroad



To get a job or into further/ higher education



To complete a walk, run or similar event



To become a Gaucher patient advocate (see the section later in this booklet)



To take up a new hobby or join an evening class

Talking to your specialist doctor or nurse

What are the goals for my treatment?

Use the next pages to note down the goals for your treatment. If you're struggling, have a chat to your nurse about what these could be, or use this book to give you some ideas.





The goals I want to achieve are...

Achieve by...



The goals I want to achieve are...

Achieve by...

[illegible]

It's important to answer these questions as honestly as you can, so you can get any appropriate help that you need. When your specialist doctor or nurse gives therapy as an intravenous infusion, they can see for themselves that you have received the right treatment at the right dose, every time. When you leave their clinic and care for yourself at home, they rely on you to tell them exactly what's been happening. Nobody would want you to struggle on silently if there's something they can do to help. Even if you've missed a number of doses, it's essential to tell your healthcare team about it – this is so that they can assess whether any improvements or problems have been due to the Cerdelga® or not.

Talking to your specialist doctor or nurse

Who To Contact



UK Treatment Centres

Birmingham

Queen Elizabeth Department of Inherited Metabolic Diseases
Heritage Building
Queen Elizabeth Hospital
Mindelsohn Way
Edgbaston,
Birmingham
B15 2TH



Telephone
+44 (0) 121 627 1627 Ext 51592

Cambridge

Addenbrookes Lysosomal Storage Disease Unit
Addenbrookes Hospital
Hills Rd
Cambridge
CB2 0QQ



Telephone
+44 (0) 1223 274 634

Salford

The Mark Holland Metabolic Unit
Salford Royal NHS Foundation Trust
Stott Lane
Salford
M6 8HD



Telephone
+44 (0) 161 701 2137

Cardiff

The Inherited Metabolic and Lysosomal Disease Service
University Hospital of Wales
Heath Park
Cardiff
CF14 4XW



Telephone
+44 (0) 29 2074 3275

Belfast

Belfast City Hospital
Genetics Department
Lisburn Rd
Belfast
BT9 7AB



Telephone
+44 (0) 2890 240 503 Ext 3874

UK Treatment Centres (Continued)

London

National Hospital for Neurology and Neurosurgery
Metabolic Disease (Adult Inherited)
Charles Dent Metabolic Unit
Box 92
Queen Square
London, WC1N 3BG



Telephone

+44 (0) 207 829 8778

London

The Royal Free Lysosomal Storage Disease Units
Pond St,
London
NW3 2QG
+44(0)207 472 6409



Telephone

+44 (0) 207 472 6409





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