

Getting ready for appointments at your specialist centre



Late Onset Pompe Disease

To make the most of your clinic appointments, it can be helpful to write down any symptoms, concerns, or questions you want to discuss with your specialist healthcare team.



You can print a copy of these pages to take to your appointments or download an editable PDF to your phone, tablet or laptop from www.pompe.uk/publications-library/appointment-sheet.

What is most important to me?

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Can you describe the symptoms and how they are affecting you?

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Are your Pompe symptoms affecting your everyday life or preventing you from doing things you enjoy?

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What changes would help you the most?

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Symptoms or concerns



Weak muscles

For example, trouble walking, climbing stairs, lifting arms, carrying things, sitting up, frequent trips and falls, relying more on mobility aids.

- Getting worse
 No change
 Getting better

Changes noticed

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Trouble eating

For example, difficulty chewing or swallowing food, experiencing choking or coughing while eating, weight loss.

- Getting worse
 No change
 Getting better

Changes noticed

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Breathing problems

Feeling out of breath easily, shortness of breath during exercise or activities, needing support with breathing devices, sleep apnoea (breathing stopping during sleep), morning headaches, snoring, daytime sleepiness, night sweats, etc.

- Getting worse
 No change
 Getting better

Changes noticed

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Heart issues

Swelling in the legs or feet, chest pain or discomfort, fast heart rate, etc.

- Getting worse
 No change
 Getting better

Changes noticed

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