

Getting ready for appointments at your specialist centre



Infantile 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 for your child?

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Are your child's Pompe symptoms affecting their everyday life or preventing them from doing things they enjoy?

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

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What changes would help them the most?

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Symptoms or concerns



Weak muscles

Changes in child's movements (for example: rolling, sitting, crawling, walking, grasping objects, moving arms/legs, supporting their head, having frequent falls, walking on tiptoes (tight Achilles tendon).

- Getting worse
 No change
 Getting better

Changes noticed

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Trouble feeding

Difficulty in sucking, swallowing or latching on during breast/bottle feeding, frequent gagging/ choking/ coughing while eating, prolonged feeding times, refusing to eat, trouble gaining weight, etc.

- Getting worse
 No change
 Getting better

Changes noticed

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Breathing problems

Any changes in breathing (shortness of breath during activity), audible wheezing or grunting, the need for ventilation, etc.

- Getting worse
 No change
 Getting better

Changes noticed

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Heart issues

Swelling in the belly, legs, or feet, a fast or irregular heartbeat.

- Getting worse
 No change
 Getting better

Changes noticed

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Enlarged tongue

Excessive dribbling.

- Getting worse
- No change
- Getting better

Changes noticed

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Developmental delays

Delays in speech, difficulty engaging with toys, etc.

- Getting worse
- No change
- Getting better

Changes noticed

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Behaviour changes

More fussiness, trouble being calmed down, being less responsive to parents, rolling eyes, reduced interest in surroundings, etc.

- Getting worse
- No change
- Getting better

Changes noticed

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Sleep problems

Trouble staying asleep, falling asleep, waking up often, snoring, waking up with a headache, night sweats, daytime sleepiness, etc.

- Getting worse
- No change
- Getting better

Changes noticed

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Frequent colds or illnesses

Getting sick more than usual, especially with breathing problems.

- Getting worse
- No change
- Getting better

Changes noticed

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Other symptoms or concerns

For example, incontinence.

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Other things I want to talk about

For example, problems with infusions, accessing treatment, school/workplace, house adaptations, transport etc.

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My notes

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