

LOPD Discussion Guide

Helping you start the conversation at your next appointment

Keeping track of your late-onset Pompe disease (LOPD) and checking in on how you're feeling is important. It can help you recognize changes and lead to meaningful conversations with your medical care team about managing your LOPD.

Take a moment to remember your most recent conversation with your doctor. Since then, have things improved, stayed the same, or gotten worse? Think about how you felt at your last appointment and how you've felt since then. When you're ready, fill in the form below and bring it with you to your next visit with your doctor.

Date of last appointment: _____
Month Day Year

Date of next appointment: _____
Month Day Year

Consider the list below and write an **X** in the **Much Better**, **A Little Better**, **The Same**, **A Little Worse**, or **Much Worse** column, depending on how much they have changed since your last appointment (write an **X** in the **N/A** column for those that don't apply). Jot down any extra thoughts you'd like to discuss with your medical care team in the **Notes** section on the back.

	Experience					
	Much Better	A Little Better	The Same	A Little Worse	Much Worse	N/A
How well I walk seems						
My ability to climb stairs is						
My ability to stand from a seated position is						
How often I use my cane/wheelchair is						
How well I breathe seems						
My reliance on breathing assistance is						
The level of fatigue I'm experiencing is						
Using my arms and hands feels						



Looking for a more in-depth symptom assessment?

Scan the QR code to fill out the Pompe Discussion Driver or visit PompeDiscussionDriver.com

