

BUILD TRUSTED PARTNERSHIPS WITH YOUR PATIENTS:

a guide to patient-centred dialogue in LSD care



This discussion guide provides you with examples of patient-focused questions to support individuals with an LSD, fostering patient empowerment and shared decision-making in their care. Use this guide during interactions with patients and feel free to add notes as needed.

To see examples of applying this guide to real-world scenarios, explore the [‘LSD clinical case examples to guide patient-centered conversations’ interactive resource on the Takeda Rare Disease Hub](#).



Understanding your patient's background

Living with an LSD presents significant emotional, cognitive, social and financial challenges, affecting not only the individual but their families and loved ones.

For patients, long diagnostic journeys and misdiagnoses can reduce trust in physicians.

Building strong, trusting relationships and delivering holistic, personalised care requires a deep understanding of each patient's background and family dynamics.

- ☐ **What's your current living situation, and do you have a caregiver or support system at home?**
 - *If unknown, seek to understand who they live with or who supports with their care, and whether anyone else in the household has a rare disease*
- ☐ **Would you like to include your carer/a support person in this conversation?**
- ☐ **Can you tell me about your educational background, or what kind of work do you do?**
 - *Seek to understand their level of education, type of work and employment arrangements (contract/permanent/full-time/part-time/shifts). Additionally, explore if their disease impacts their work and/or education, and whether their current employment or educational path aligns with their personal goals and aspirations*
- ☐ **What activities do you enjoy or aspire to do?**
- ☐ **How long have you been living with an LSD?**
- ☐ **How long before your diagnosis did you experience symptoms of an LSD? What was that experience like?**



Understanding your patient's relationship with their LSD

Symptoms of an LSD are often progressive and vary by specific condition and age of onset.

They profoundly impact quality of life, evolving over time or in response to treatment.

Beyond physical symptoms, living with a rare disease can have far-reaching effects – placing strain on families and relationships, affecting a patient's sense of self, and contributing to feelings of isolation and loss of hope for the future.

- ☐ **How well do you feel you understand your LSD?**
 - *Ask about both the medical and personal aspects*
 - *Explore any areas they feel confused or unsure about*
- ☐ **What symptoms of an LSD have you been experiencing?**
- ☐ **What activities, if any, have you wanted to do recently but couldn't due to your symptoms?**

- ☐ How do you feel about your LSD/about living with an LSD?
- ☐ How, if at all, has your LSD affected your sense of self?
- ☐ What impact, if any, does your LSD have on your enjoyment and sense of purpose in life? If so, how?
- ☐ Are your relationships affected because of your LSD? If so, how?



Understanding your patient's unmet needs

Managing a rare disease can be time-consuming, costly and disruptive – often requiring travel and time away from work and loved ones.

Some patients may struggle to perceive the benefits of treatment while also experiencing significant side effects such as infusion reactions.

Open and transparent discussions about treatment risks and benefits can support informed decisions, but it's equally important to give patients time and space to process information about their care and consider the options available to them.

- ☐ What would your family, friends or carer want to say to me on your behalf?
- ☐ What are your priorities for living with your LSD? What about for managing your symptoms?
 - *Seek to understand what would help them to manage their symptoms and make living with their LSD easier*
- ☐ What could I do to help you understand your treatment options?
- ☐ How do you prefer to receive information?
- ☐ What role do you want to play in making decisions regarding your care?
- ☐ What support would you like to receive before/during/after making those decisions?
- ☐ What can we put in place to support you better at our next appointment?

Notes

HCP, healthcare professional; LSD, lysosomal storage disorder.

References:

1. NICE guideline. Shared decision making. Published 17 June 2021. Available at: <https://www.nice.org.uk/guidance/ng197/resources/shared-decision-making-pdf-66142087186885>. Accessed: April 2025. **2.** EURODIS. Rare Barometer questions repository. Published July 2022. Available at: <https://www.eurordis.org/publications/speak-up-listen-up-follow-up-guide-a-brief-guide-for-rare-disease-patient-organisations-on-how-to-listen-to-the-community/>. Accessed: April 2025. **3.** McDool E, et al. *Orphanet J Rare Dis.* 2024;19:252.

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