

BUILD TRUSTED PARTNERSHIPS WITH YOUR PATIENTS:

8 actions to enhance LSD care



The WHO defines patient empowerment as “a process through which people gain greater control over decisions and actions affecting their health”.¹ This definition highlights the importance of individuals actively participating in their healthcare management, leading to improved health outcomes and enhanced quality of life.

1 CREATE TRUSTED PARTNERSHIPS WITH PATIENTS AND FAMILIES

by involving patients in open, empathetic discussions about treatment/care options, evidence, benefits and risks



2 ACCOMMODATE INDIVIDUAL PATIENT UNDERSTANDING AND EXPERIENCES

where possible, recognising differing levels of health literacy and the psychosocial impact of living with an LSD, including heightened stress and anxiety



3 MINIMISE DISRUPTION TO NORMAL FAMILY LIFE

by being flexible and working with families to fit appointments, treatments, etc. around their schedules



4 FOSTER A COLLABORATIVE APPROACH

that supports fully informed consent and free patient choice, recognising that patients are more likely to engage when they feel empowered rather than coerced



5 USE MOTIVATIONAL INTERVIEW TECHNIQUES, TECHNICAL SKILLS TRAINING AND COACHING IN PROBLEM-SOLVING

to build rapport, encourage change, support autonomy and target interventions



6 PROMOTE REALISTIC OPTIMISM

and provide quick feedback and encouragement to promote confidence and self-efficacy



7 BE A TRUSTED SOURCE OF QUALITY-ASSURED INFORMATION

regarding the disease, treatments and outcomes. Check the patient's knowledge and encourage them to ask questions



8 SUPPORT PATIENTS IN ACCESSING SPECIALISED SERVICES AND RESOURCES

such as the National Rare Diseases Office, as well as the MPS Society and Rare Minds,* and coordinate multidisciplinary care to form robust patient pathways



*Rare Minds provides a counselling service that is free to MPS Society members. This is a confidential service available to both patients and families who are over 18 years old. More information can be accessed via the MPS Society website.²

HCP, healthcare professional; LSD, lysosomal storage disorder; MPS, mucopolysaccharidoses; WHO, World Health Organization.

References:

1. Health promotion glossary. Overview. Published 16 June 1998. Available at: <https://www.who.int/publications/i/item/WHO-HPR-HEP-98.1>. Accessed: April 2025. 2. MPS Society. Rare Minds counselling service. Available at: <https://mpssociety.org.uk/support-we-offer/mental-health-and-wellbeing/telephone-online-counselling-service#how-do-i-access-counselling>. Accessed: April 2025.

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