BUILD TRUSTED PARTNERSHIPS WITH YOUR PATIENTS:

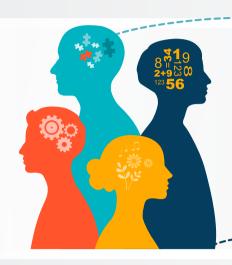
8 actions to enhance LSD care

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

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





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

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

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





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





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

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.

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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