

COMMUNICATING WITH YOUNG ADULTS WITH MPS

Young adults with MPS often navigate complex healthcare systems while developing greater independence and self-management skills. Effective communication helps build trust, supports informed decision-making, and promotes successful transition to adult care.

1. Principles of Patient-Centred Communication



Use Clear and Accessible Language

Young adults with MPS may have complex medical histories involving multiple specialists and treatments. Use plain language when explaining diagnoses, procedures, and care plans, and regularly check for understanding.



Communicate Directly with the Young Adult

While family members often play an important role, healthcare professionals should speak directly to the young person whenever possible, encouraging participation and self-advocacy.



Support Shared Decision-Making

Involve young adults in discussions about their care, treatment options, and future planning. Encourage questions and ensure they understand the choices available to them.



Build Trust Through Respect

Listen actively, acknowledge concerns, and create space for honest conversations about fears, goals, and challenges.

2. Common Communication Challenges & Practical Strategies

Challenge	Communication Approach
Complex clinical needs and medical histories	Use clear language, provide written summaries, and check understanding regularly.
Parent involvement in care	Respect the family's role while gradually encouraging independence and direct communication with the young adult.
Anxiety about adult services	Explain changes step-by-step and provide reassurance about ongoing support.

Limited preparation for transition		Use checklists, guides, and early planning conversations to build confidence.
Concerns about new healthcare teams		Introduce adult providers early and use joint appointments when possible.
Lack of coordination between providers		Clearly explain team roles and encourage shared communication across services.
Limited access to adult MPS specialists		Be transparent about expertise and promote collaborative care between teams.
Concerns about self-management		Break information into manageable steps and celebrate progress.

3. Discussing Sensitive Topics

Sexual Health and Relationships

Create opportunities for private conversations and use non-judgmental language.

Mental Health and Emotional Wellbeing

Recognise anxiety around transition, independence, and future planning.

Dependence and Independence

Support realistic goal setting while recognising individual support needs.

Future Planning

Encourage open conversations about education, employment, living arrangements, and long-term goals.

4. Cultural Sensitivity and Accessibility

Healthcare professionals should:

✓	Respect cultural differences and family dynamics
✓	Use interpreters when needed
✓	Provide accessible formats and easy-read information
✓	Consider hearing, speech, cognitive, and physical accessibility needs
✓	Adapt communication methods to individual preferences

5. Empowering Young Adults

Young people are more likely to engage in their care when they are encouraged to:

- Ask questions
- Understand their condition
- Manage appointments
- Know their medications
- Participate in decisions
- Advocate for their needs