

CASE STUDIES FROM MPS ADULTS

These case studies highlight the real-life experiences of young people with MPS transitioning from paediatric to adult healthcare services. While every journey is unique, these examples demonstrate common challenges, successful approaches, and key considerations for healthcare professionals supporting transition and long-term care.



Case Study 1: **MPS I (Hurler Syndrome) with Immune Complications**

A young man with MPS I experienced multiple health challenges, including recurrent infections, hearing loss, vision impairment, hip problems, and severe learning difficulties.

Transition planning began at age 15 and included three dedicated transition clinic visits over an 18-month period.

Structured tools such as a Transition Passport and Ready Steady Go checklist were used to support the process.

At age 20, he remains clinically stable, receives regular immunoglobulin therapy, and has had no recent hospital admissions.

Challenges

- Complex multisystem disease
- Multiple specialist teams involved
- Severe learning difficulties
- Ongoing immune treatment requirements
- Coordinating information across services

What Helped



- Early transition planning
- Dedicated transition clinics
- Transition Passport
- Ready Steady Go checklist
- Family involvement
- Coordination between healthcare teams

Key Takeaway for Healthcare Professionals

Early preparation, structured transition tools, and multidisciplinary coordination can improve continuity of care and support positive outcomes for young adults with complex healthcare needs.

Case Study 2: MPS I (Severe Form) with Emotional Delay

A young woman with severe MPS I experienced significant skeletal, cardiac, respiratory, and ophthalmological complications.

After transferring from another hospital at age 16, she required a comprehensive reassessment of her healthcare needs.

She was emotionally immature for her age, remained highly dependent on family support, and expressed significant anxiety about moving into adult care services.

Transition planning began at age 18 and included early meetings with adult providers and psychological support. She transferred to adult services at age 19.

She sadly passed away at age 22 due to respiratory complications.

What Helped



- Early engagement with adult services
- Psychological support
- Family-centred transition planning
- Comprehensive reassessment
- Gradual introduction to adult providers

Challenges

- Complex multisystem disease
- Emotional immaturity
- Dependence on family support
- Anxiety regarding adult services
- Transfer from another healthcare centre

Key Takeaway for Healthcare Professionals

Transition readiness should be assessed emotionally as well as medically. Young adults may require additional psychological support and flexible timelines to successfully navigate adult care.

Key Lessons from MPS Transition Experiences

✓	Start planning early
✓	Involve patients and families throughout the process
✓	Address emotional as well as medical readiness
✓	Promote collaboration between paediatric and adult providers
✓	Recognise that every transition journey is unique

