

This resource explores reproductive and sexual health for people with MPS, guided by both lived experience and therapeutic expertise. It aims to provide clear, respectful, and empowering information around body awareness, intimacy, communication, and reproductive decision-making.

This content is informed by Mia, a therapist, educator, and advocate living with MPS I, whose work focuses on relationships, disability, and intimacy.





1. Managing Reproductive Health

Mia highlights that sexual and reproductive health is much broader than pregnancy or intercourse. It includes:

- Menstrual health
- Pain management
- Pelvic health
- Incontinence
- Bodily autonomy

People with MPS are often excluded from this education due to harmful assumptions about disability and sexuality. Building confidence starts with learning to advocate for yourself in healthcare settings.

Key Guidance

	Write down questions before appointments
	Bring a trusted person if helpful
	Practice speaking about your health needs
	Stay in control of your medical conversations

2. Puberty and Menstruation

Mia explains that puberty and body changes can feel more complex when living with a chronic condition. Pain, body differences, and medical attention can sometimes make people feel disconnected from their bodies.

She encourages reframing this experience:

- Your body is not only medical — it is also personal and lived-in
- You are allowed to feel ownership and comfort in your body
- Questions about your body are valid at every stage

Key Message



Understanding your body early helps build long-term confidence and self-trust.





3. Sexual Health Conversations

Mia challenges the misconception that disabled people are either “asexual” or “hypersexual.” These stereotypes can prevent honest conversations and limit access to proper education.

Sexual health includes:

- Pleasure and intimacy
- Consent and boundaries
- Emotional connection
- Communication and trust

Key Guidance

	Practise conversations out loud
	Ask questions without shame
	Learn from trusted community voices
	Remember: sexual health is more than intercourse

4. Healthcare Professional Communication

Confidence in healthcare settings is a skill that can be built over time.

Mia encourages:

- Preparing questions in advance
- Practising how to express needs
- Using “I feel” statements
- Bringing support if needed

She emphasises that many people with MPS experience gaps in care due to assumptions about disability — so self-advocacy is essential.





5. Family Planning and Relationships

Mia explains that family planning looks different for everyone. Pregnancy may be possible for some people with MPS, but it can involve significant risks and requires careful planning and support.

She highlights:

- Open conversations with partners
- Honest discussions about expectations and fears
- Building support systems early

Options May Include

	Pregnancy (with medical guidance)
	Adoption
	Fostering
	Choosing to remain childfree

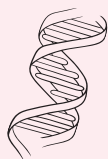
All paths are valid.

6. Genetic and Relationship Counselling

Mia distinguishes between two important forms of support:

Genetic Counselling

- Medical information
- Risk and inheritance
- Pregnancy planning support



Relationship/Intimacy Counselling

- Emotional processing
- Communication support
- Identity and intimacy concerns







Together, they support both practical decisions and emotional wellbeing.

7. Intimacy and Body Changes

Mia explains that intimacy is not static — it changes over time, especially with MPS. Counselling can help individuals and couples:

- Adapt to physical changes
- Process grief around body changes
- Explore comfort and pleasure safely
- Rebuild connection in new ways

Intimacy can include:

	Touch
	Emotional closeness
	Presence
	Affection

Not just sexual activity.

8. Communication and Relationships

Mia highlights communication as the foundation of intimacy.

Key practices:

- Regular relationship check-ins
- "I feel" statements instead of blame
- Celebrating positives, not just addressing challenges
- Being honest about needs and limits



9. Final Message

Mia's message to young people with MPS is clear and affirming:

*You are not defined by assumptions about your body or disability.
Love, intimacy, and connection are not rare or out of reach.
Pleasure matters more than performance.
You are worthy of love exactly as you are.*

10. Suggested Reading (Mia's Recommendations)

Sex & Intimacy

Come As You Are — Emily Nagoski
Come Together — Emily Nagoski
She Comes First — Ian Kerner
He Comes Next — Ian Kerner

Personal Development

How to Keep House While Drowning —
KC Davis
Burnout — Emily & Amelia Nagoski

Relationships & Communication

Who Deserves Your Love — KC Davis
Fair Play — Eve Rodsky

Disability & Lived Experience

Afraid of the Doctor — Meghan L.
Marsac & Melissa J. Hogan
This Is Body Grief — Jayne Mattingly
Disability Visibility — Alice Wong

