

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 draws on the professional expertise and lived experience of Samantha.



Samantha is a therapist, educator, and advocate specializing in relationships, disability, and intimacy (MA, LPCC, MFTC). Her lived experience with Mucopolysaccharidosis (MPS) Type 1 has shaped her life and made her passionate about inclusivity. She helps others navigate challenges related to disability, chronic illness, and neurodivergence. She values radical authenticity and encourages others to embrace every aspect of themselves.

As she moved through both medical and academic spaces, she became acutely aware of what was missing. Conversations about sexuality, intimacy, and disability were often absent or treated as an afterthought. She also saw how medical trauma quietly weaves itself into interpersonal relationships, shaping trust, communication, and attachment in ways people do not always recognize.

Her work now centers on supporting individuals, couples, and families as they navigate disability, chronic illness, medical trauma, and intimacy.

She helps clients untangle the relational patterns shaped by these experiences and build relationships grounded in safety, connection, and self-trust. At the same time, she advocates for the normalization of disabled sexuality and the inclusion of these conversations in comprehensive sex education and healthcare spaces.

## 1. Managing Reproductive Health

Samantha 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

Samantha 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

Samantha 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. Samantha 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

Samantha 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      |

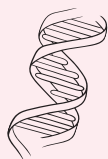
All paths are valid.

## 6. Genetic and Relationship Counselling

Samantha 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

Samantha 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

Samantha 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

Samantha'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 (Samantha'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

