

Building a strong support network can make a meaningful difference when living with MPS. This guide explores how to stay connected with peers, mentors, healthcare teams, and advocacy groups, and why these connections matter.

## 1. Connecting with the Right Support Networks

Connecting with the right support networks can make a significant difference when living with a rare condition like MPS. Whether you are seeking information, emotional support, practical guidance, or opportunities to connect with others who share similar experiences, there are a range of organisations and resources available to help.

### **MPS Society UK**

Offers information, resources, events, and community support for individuals and families affected by MPS.

### **International MPS Network (IMPSN)**

Connects individuals, families, and organisations worldwide, providing a global network of support, advocacy, and shared experiences.

### **Metabolic Support UK**

Provides information, guidance, and support for people living with inherited metabolic conditions, including MPS.

### **Rare Minds Mental Health Support**

Offers mental health support, counselling, and guidance for people living with rare diseases and their families.

### **Local MPS Support Groups**

Explore organisations and support groups within your own country or region to access local resources, events, and peer connections.

## Global MPS Organisation Directory

### IMPSN 2025 Contact List

[VIEW THE LIST →](#)

## 2. Support Networks in MPS Care: Why They Matter

Support networks are vital for people living with MPS, as well as their families and carers, because MPS is a rare, lifelong, and complex condition that affects many areas of daily life.

### Why support networks are important

MPS can feel isolating. Many individuals and families may never meet someone else with the same condition, which can lead to loneliness, fear, and feeling misunderstood.

Support networks help create a sense of belonging by connecting people who truly understand the challenges of living with MPS. They also help families navigate complex healthcare systems and cope with the emotional impact of diagnosis, progression, and uncertainty.

### How support networks can help

Support networks provide a space to:

- Share experiences and ask questions
- Learn from others in similar situations
- Build confidence in managing daily challenges
- Access practical knowledge and advice
- Reduce stress, anxiety, and caregiver burnout

## What support networks can offer



### Emotional Support

Listening, reassurance, and shared understanding.



### Practical Support

Advice on treatments, therapies, mobility aids, education, benefits, and daily care.



### Information & Education

Reliable resources, research updates, and specialist services.



### Social Connection

Friendships, community events, and reduced isolation.



### Advocacy & Empowerment

Supporting voices in healthcare, education, and policy settings.



## Key takeaway

Support networks help individuals with MPS, families, and carers feel less alone, more informed, and better equipped to face the challenges of a rare condition together.

## 2. Connecting with Others

Social media and community platforms can be powerful tools for connection.

Consider joining:

- Instagram communities
- Facebook groups
- WhatsApp groups

**In addition to online support, maintain contact with:**

- Consultants and specialist nurses
- Care or support teams
- Friends, family, and neighbours

Building both online and personal connections helps create a stronger, more balanced support system.

## 3. Staying Connected with Peers

- Rare disease online communities (Facebook, WhatsApp, Discord)
- Check-in buddy systems for regular support chats
- Patient meetups and conferences (virtual or in-person)
- Sharing strategies for daily challenges and coping



## 4. Finding Mentors



### Peer Mentors

Connect with others who have lived experience of MPS or similar journeys.



### Healthcare Mentors

Build relationships with professionals who understand rare disease care pathways.



### Advocacy Mentors

Learn from experienced advocates involved in awareness, campaigning, and policy work.

Because MPS is rare, mentors may not always have ready answers, but they can help you think through decisions and feel less alone

## 5. Engaging with Advocacy Groups






You can get involved by:

- Joining rare disease organisations (e.g. MPS societies, Genetic Alliance UK, Metabolic Support UK)
- Volunteering (writing, speaking, event support)
- Raising awareness during Rare Disease Day and campaigns
- Staying informed through newsletters and updates

## 6. Digital Tools for Connection

- Zoom & Microsoft Teams for virtual groups
- Social media platforms for community engagement
- Calendars and reminders to manage energy and pacing

## 7. Tips for Sustaining Your Network

	Consistency matters more than intensity
	Be open about your needs
	Balance giving and receiving support
	Celebrate small wins and milestones
	Stay connected in ways that feel manageable

## 8. Final Takeaway

Living with MPS can feel isolating, but you do not have to face it alone. By connecting with peers, mentors, healthcare professionals, and advocacy groups, you can build a strong support network that provides strength, understanding, and connection throughout your journey.

