

SUPPORT AND ADVOCACY TEAM

# A guide on palliative and supportive care



**MPS Society**

transforming lives through  
support, research & awareness

Society for Mucopolysaccharide Diseases  
[mpssociety.org.uk](http://mpssociety.org.uk)





## Understanding palliative care

Palliative care is a caregiving approach aimed at optimising quality of life and reducing suffering for people with chronic and often terminal illnesses.

Palliative care is about more than just end-of-life care, it's about making every day as comfortable, meaningful and fulfilling as possible, no matter where you are on the journey. It can provide relief from pain and symptoms, offer emotional and practical support and help families navigate the complexities of living with a long-term, life-limiting condition. The approach should be holistic, putting the person with the condition at the centre and ensuring their physical, emotional and spiritual needs are met.



## The role of hospice and supportive care

Hospices are places of respite, support and comfort. Although supporting families at end-of-life is an aspect of their work, hospices are so much more and often work with individuals and families over many years.

They offer a safe and welcoming environment where families can take a break while ensuring their loved one receives specialist care.

Many hospices offer:

- **Short breaks and respite stays**
- **Expert symptom management**
- **Emotional and psychological support**
- **Sibling and family support services**
- **Music, art and play therapy**
- **Spiritual and holistic therapies**

For families living with MPS and related conditions, accessing hospice care early can provide reassurance and a supportive network that remains in place for years.

# Palliative care team

A palliative care team is a group of professionals who work alongside families and healthcare providers to ensure that every aspect of care is personalised.

This might include health and social care professionals such as physiotherapists, occupational therapists, palliative care nurses and many others.

These professionals might work in your home, in hospital, in a care home or in a hospice and will:

- **Manage symptoms such as pain, respiratory issues and feeding difficulties**
- **Support mobility and physical comfort**
- **Help with decision-making about treatments and interventions**
- **Offer counselling and mental health support**
- **Connect families with community services, advocacy groups and financial support**

Every family's journey is unique, and palliative care adapts to meet their needs. The focus of palliative care teams is always to enhance quality of life.

## The importance of advanced care planning

Planning ahead can be difficult, but it is one of the most empowering things that families can do.

Making decisions about treatments or interventions during a medical emergency can be extremely difficult. Advanced care planning means discussing your preferences around treatments and interventions and ensures that your wishes, and those of your loved one, are respected at every stage.

This process includes:

- **Discussing preferences for medical care and interventions**
- **Understanding legal documents such as Advance Decisions to Refuse Treatment (ADRT)**
- **Appointing a trusted person to make decisions if needed**
- **Exploring options for home, hospice or hospital-based care**
- **Ensuring emotional and spiritual needs are considered**

By making plans in advance, families can focus on what truly matters, spend quality time together and ensure their loved one's journey is as peaceful and dignified as possible. Healthcare teams and palliative care professionals are there to guide and support you every step of the way.

The MPS Society Support and Advocacy Team can also provide support in navigating this process.



# Support for the whole family

Living with MPS and related conditions affects the whole family, and support is available for everyone whether it's parents, siblings, grandparents or extended family.

Having a strong support system can make all the difference. Many services exist to help families navigate the emotional and practical aspects of palliative care, including:

- **Counselling and bereavement support**
- **Peer support groups**
- **Respite and short breaks**
- **Financial and practical advice**

We can support you by directing you to some of these services. Remember you are not alone, reach out to our Support and Advocacy Service at any time.

# MPS Society Support and Advocacy

Find out more about the support available and contact the MPS Society in whichever way suits you.

Phone us on **0345 389 9901**

Email us at **[advocacy@mpssociety.org.uk](mailto:advocacy@mpssociety.org.uk)**

Join our community **WhatsApp** group and monthly **virtual coffee mornings**.

Scan to join on **WhatsApp**



Help is always available and no family should have to face this journey alone.

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