SUPPORT AND ADVOCACY TEAM Supporting you through bereavement



Society for Mucopolysaccharide Diseases mpssociety.org.uk



Bereavement support

Losing a loved one is an incredibly difficult experience and we understand how deeply it affects you, your family and your community. During this challenging time, we are here to listen, support and guide you through your grief.

If you would like to speak to someone confidentially, our Support and Advocacy Team is available to offer emotional and practical support, guidance, resources and information.

How to get in touch

Phone us on 0345 389 9901

Email us at advocacy@mpssociety.org.uk

Join our community WhatsApp group and monthly virtual coffee morning for bereaved members.

Scan to join on **WhatsApp**



We also offer onward referral and access to specialised counselling and grief services.

- Rare Minds Counselling Service is a free, confidential service for MPS Society members at mpssociety.org.uk/rare-minds
- GriefChat is a free online chat service with trained bereavement counsellors available Monday to Friday, 9am– 9pm via mpssociety.org.uk/grief-chat

Ways to remember

We know how important it is for families to remember their loved one and have a place to feel close to them. These are some meaningful ways to help cherish treasured memories.

The **Wood of Remembrance and Hope** in Sherwood Forest was planted in 1993 with oak saplings cloned from the forest's Great Oak. It serves as a lasting tribute to those who have lost their lives to MPS or related conditions and is a place for families to visit and feel close to them. There are:

- Planting Days where bereaved families can plant a tree in memory
- Memory Boards featuring names and messages from families
- Annual bereaved family weekends in September offering time to gather, reflect and support one another

A memory box or jar can hold photographs, poems, letters and personal items or could be filled with layers of coloured sand that symbolise special memories.

Writing down memories, thoughts or even letters in a **memory book or journal** can help with grief and provide a keepsake for the future.

Lighting a candle on special days can be a simple yet powerful way to honour their memory.

Visit our website for more ideas.

Creating an **online tribute** can be a personal way to remember someone special. We have partnered with **MuchLoved** where you can create a tribute page that allows you to share memories, photos, music, light virtual candles and mark special anniversaries as well as raise vital funds for the **MPS Society**. **mpssociety.muchloved.org**

In partnership with much loved The In-Memory Platform

Financial assistance

When a loved one passes away there may be unforeseen expenses that are difficult to meet.

We are able to offer bereavement support payments of £150 to the primary carers of an individual diagnosed with an MPS or related condition who has been an MPS Society UK member. Access to this payment does not require a means test and is available up to one year following their death. Access this payment by contacting your Support and Advocacy Officer or start by completing this form.

Scan to access the **form**



Additional bereavement support resources

- Cruse Bereavement Care Support for children, young people and adults
- Child Bereavement UK Support for those facing the loss of a child or young person
- **Grief Encounter** Support for bereaved children and young people
- Hope Again Youth-focused bereavement support
- **Sue Ryder** Online bereavement support and professional counselling
- The Compassionate Friends Support for bereaved parents and families
- The Samaritans 24/7 emotional support
- **SHOUT** A confidential mental health text service (Text **SHOUT** to **85258**)

Society for Mucopolysaccharide Diseases

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