

Finding your way with bereavement

for people affected by MND



**“Grief is as individual
as a snowflake.”**

Jude Sellmeyer, former carer to her son.

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“This booklet really captures what can be said about grief. I really like the quotes from other bereaved people.”

Gwyneth Peden, Trust Bereavement Co-ordinator,
Northern Health and Social care Trust, Northern Ireland.

“This booklet has lots of great information about bereavement and grief.”

Becky Popperwell, Media and Campaigns Manager,
Cruse Bereavement Care.

**This information has been evidenced,
user tested and reviewed by experts.**



Patient Information Forum

How can this booklet help me?

This booklet is designed to help you, your family and friends find emotional support after your loved one has died from motor neurone disease (MND). We have also included a practical overview of what to do when someone dies. Our **End of life** guide provides more detail, including financial and legal guidance. You can find out how to order this and our other resources in section 7: *How do I find out more?*

See section 8: My pages for space to note down any thoughts, feelings or 'to do' lists.



This symbol highlights quotes from bereaved carers who have shared their experiences with us.

We recognise that people from different faiths have different ways of grieving. There may be mourning periods or rituals to observe. Your community faith leaders or a local hospice organisation may be able to help.

We are here to support you

Our MND Connect helpline can also offer guidance and emotional support by phone or email. The team can direct you to specialist organisations if needed:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

See our web page about bereavement support at:
www.mndassociation.org/bereavement

Our online forum provides a safe place to share support with others, including a section for people bereaved by MND:

<https://forum.mndassociation.org>

1: When does grieving begin?



“Our grieving started once my husband was diagnosed.”

With MND, a sense of loss is often felt throughout the disease. This is known as anticipatory grief. You and the person with MND may have felt as though you were challenged by the condition, week by week.

What is anticipatory grief?



“ I didn’t recognise anticipatory grief, I was just scared all the time!”

Anticipatory grief can include a range of emotions, such as:

- grief and sadness over a long period of time
- a deepening distancing from the person
- a sense of dread for the future
- sorrow for the person with MND as they grieve for their own loss
- personal loss, if you gave up work or activities important to you.

This can be emotionally and physically draining for everyone involved.



“My son had grief counselling from the hospice to enable him to talk about his death, dying, and his fears, while he was alive.”

How you react to the diagnosis, the way MND progresses, and the death of your loved one will be very personal to you.

You may have:

- been in denial about the diagnosis and felt that to accept it would mean giving up on your loved one
- wished that a cure would be found in time.

Sometimes a diagnosis of a life-shortening illness gives time to reflect, make up for past disagreements, and let each other know how you feel.

Anticipatory grief is unlikely to fully prepare you for the death and you may be surprised at the intensity of your feelings when it does happen.



“With MND, you know death is coming, but you never truly know death until it happens. Nothing can prepare you for it.”

However, the challenges and losses of MND can help you develop ways to cope with these feelings.

The impact of grief and bereavement

The emotional impact of grief can take its toll on your health, particularly after the physical demands of being a carer.



“Be aware of the effect the death might have on your health. The shock of suddenly not being a carer and having to deal with certificates, registration, stopping pensions before more payments are credited, notifying family and friends, fielding telephone calls and arranging a funeral can be very stressful.”

See section 6: *What needs to be done when someone dies?* for some of the practical tasks that need completing after a death.

Grief doesn't just affect emotions or cause anxiety. Physical reactions, such as tiredness, difficulty sleeping or a tight chest are common.

You may even find daily routines more difficult. Recognising symptoms of grief may help you feel less worried and more able to manage them. If they don't go away or they become overwhelming, contact your GP, who can offer help if needed, such as:

- reassurance and appropriate action
- referral to specialist help or counselling
- a health check if you feel physically and emotionally exhausted, especially after providing care.



"I wish I had made more effort to look after myself, that is very important."

"Sometimes people worry about developing similar symptoms to the person who has died. Often physical ill health can be a symptom of grief...It's important to recognise that you need to take care and look after yourself more than you would normally."

The British Psychological Society

Why did the person seem to change?

Sometimes people with MND seem to 'change' personality. This may be because they were frightened or frustrated with the symptoms of MND. However, the disease itself can change the way some people think and behave.

This is usually mild. However, a small number of people develop frontotemporal dementia (FTD), which can be very hard to deal with. It can cause more extreme personality changes, such as aggression or problems with reasoning.



“It was stressful and terribly upsetting, so that when she died, there was only residual grief left, but the stress was still there and made worse by the activities immediately following her death.”

It may help to know that changes to thinking and behaviour are usually due to the disease, not the person you knew.



I think there may have been some behavioural changes from the disease towards the end, which were hard. But I knew the love was always really there.”

If you want to talk about how this has affected you, contact your GP, or our helpline MND Connect.

See *Further information* in section 7: *How do I find out more?* for MND Connect contact details.

2: What emotions are likely?

Mood swings are common in bereavement, but they can make you feel out of control. Difficult emotions can be overwhelming, and you may switch between feeling excitable and tearful. Recognising the emotions felt with grief, and knowing these are natural, may help.



“Grief is very individual and not everyone will go through every emotion, but an awareness of those emotions is valuable.”

These emotions usually ease in time, but this adjustment can not be rushed. If they do not ease, or if they become more intense, a bereavement counsellor or grief support worker from a bereavement support organisation can help you work through them.



How do I recognise what I'm feeling?

Shock: In the first days and weeks following a death you may be too shocked to feel anything, even where death was expected. It can take time to overcome this. Sometimes physical reactions can happen, like shaking, your heart pounding, not sleeping, exhaustion or feeling sick. Try not to take on too much at this time.



“You’re in such a fog when the person is dying.”

Anger: You may feel angry at everyone involved in the person’s care, anyone getting on with life while you are grieving, or people who don’t seem to understand how you feel. This is common, and releasing anger in a safe way can help reduce destructive feelings. Find a space to shout, scream or exercise, or try something physical like gardening.

Relief: You may feel a sense of relief, which can be confusing, but this is a natural response. The person has been released from the symptoms of MND and you have been released from seeing the effect these had on them. If you were a carer, the often overwhelming demands of the caring role have now eased. This relief can then lead to feelings of guilt, but try to recognise the support you have given, and allow yourself time to recover. A sense of balance usually returns.



“For me, the feeling of relief that he didn’t have to suffer any more and I could be free again was tremendous. But then I felt terribly guilty.”

Regret: You may wish you had done things differently or said certain things to the person. You may go over events, wishing you could make it better. This can be intense if the death was sooner than expected. Regret can be difficult to admit, but talking can be positive. You cannot get answers from the person who has died, but family and friends who knew them can often help.

Anxiety or panic: It is common to feel more vulnerable after a death, and you may worry that other people you love will become ill. These thoughts usually ease with time, but if they become more intense, contact your GP who can refer you to a specialist.

Longing: Yearning for the person to still be alive can be very intense in the early period after their death. You may grieve for unfulfilled dreams and plans you had with your loved one. Allow yourself time to adjust.

Loneliness: You may feel as if no one understands what you are going through, and wonder why it's happening to you. You may have had lots of contact with health and social care professionals which stops when the person dies. Grief can make you feel very alone. Although it may take time, social contacts are usually renewed, or new ones gained.



“Libraries are now a good way of meeting new people, they have various groups like knit and chatter, colouring, history and card games. It’s a lovely way to meet like-minded people.”

Sense of presence: You might sense the person’s presence, or hear their voice and footsteps after death. The person may also appear in your dreams. This may be comforting or upsetting, but try not to be worried if it happens to you, as many people experience this.

Are these feelings normal?

You may worry that your grief is not 'normal', but everybody's grief is an individual response. Your time with your loved one, the unpredictable challenges of MND, and your reaction to bereavement will be unique.



“Grief is as individual as a snowflake.”

Grief can feel very distressing, isolating and confusing, and there is no right or wrong way to express it. Crying can provide an outlet for tension, but is not the only way to express grief. How you react is likely to be influenced by:

Beliefs: Your opinions, moral viewpoint, faith or values.

Cultural and family background: Your upbringing, way of life and social values.

Personality: Your own personal preferences and sense of self.

Relationship with the person who died: Your connection with them will affect how you feel about their death.

Relationships with others who are close: The feelings of other people may affect how you express your grief, for example when young children are involved.

People might talk about the 'stages of bereavement', such as denial, anger, bargaining, depression and acceptance. Some people find they switch between thoughts about the future and thoughts about the loss. However, everyone is different and there is no fixed way to grieve. Allow yourself to grieve in the way that best helps you to cope.



“Managing grief is intensely personal and other people’s experiences shouldn’t be used as a template for your own grief.”



Is it okay to talk to people about what has happened?

Your grief is personal and you have a right to keep it private. You may prefer to grieve on your own, without worrying about becoming emotional in front of someone else. However, talking about how you feel may provide release and help you come to terms with the death.



“Friends from my church were very kind when I told them how I felt, so I realised I had to ask for help and not just keep things to myself.”

It can be a difficult conversation to open with someone, especially if:

- you're worried about how the death is affecting them
- family and friends avoid the subject for fear of upsetting you
- people don't know what to say.

Saying *'I'd like to talk about them'* may help people feel more comfortable to start conversations. Talking about the person can help keep their memory alive. Seek out those who want to talk, or a support group, counsellor or helpline.

Sometimes, talking to someone you don't know can enable a more open conversation. Writing down how you feel may also be helpful.

See section 8: *My pages for space at the end of this booklet.*

Some people find virtual support groups helpful places to talk. The MND Association has an online forum, including a bereavement section, where people living with and affected by MND share experiences and support: **<https://forum.mndassociation.org>**
You don't have to sign in if you do not want to post on the forum.

What do I do if the grief doesn't go away?

Grief can last a long time and will always be a part of who you are. Yet adjustment can help you gradually accept and work through these emotions, which usually become less intense. Routines and socialising may feel easier again in time. Grief can persist for some people, which could impact on your health if you don't receive the right support for you.

If grief disrupts your everyday life, seek support. For example, if you still find it difficult to manage daily activities like washing and dressing several months after the bereavement, ask your GP about referral for specialist help or counselling.

Referral is not usually made in the first couple of months following a death unless there is a severe need, as emotions are naturally more intense during this time. However it is worth asking if you do feel you need extra support and to know help will become available in time. You can also pay privately for counselling if you wish, but take advice from your GP about how to seek qualified help.

Will the grief return?

You may feel sad at special events, months and years after the persons death. This is a natural response that many people experience. Certain situations, songs or even smells can trigger emotional responses that may be momentary or last for days.



“I've had to pull over in the car a few times when certain pieces of music come on the radio.”

This does not usually mean you are going to begin the grieving process all over again. However, if you find repeated waves of emotion difficult to manage, your GP can help at any stage of grief.

3: Who can support me?

Wanting to be alone at this time is natural, but you may need support to deal with the impact of the illness and death of your loved one. If you lived with the person who had MND, there may have been many visits from health and social care professionals to your home. These stop when the person dies, which often feels isolating.

Family and friends can give vital emotional and practical support at this time. After the death of a loved one, visits from friends and family sometimes reduce, but you can explore the relationships you want to maintain or rebuild.



“There was no debrief after he died, everything just stopped.”

Support is available and you do not have to be alone:

Your GP: Can give you a health check, they may refer you for specialist support, if needed. They often have information about wider grief support in your local area.

Palliative care professionals: If the person with MND was supported by palliative care specialists, such as in a hospice or hospital, they usually offer bereavement support to you and immediate family (this may include children and young people).



“I am so lucky to have the hospice. One and a half years since his death and they’re still supporting me.”

MND Connect: Our helpline team provides information, emotional support and help to access our services and other organisations.

For contact details see *Further information in section 7: How do I find out more?*

Association visitor (AV): If you were supported by an AV, they can continue this into bereavement, if it feels right for you both. Many AVs are bereaved carers, and may have a personal experience of what you're going through.

MND Association branches and groups: Our local branches and groups offer guidance and support, and often get together for meetings or events. Some bereaved carers or family continue accessing this type of support, and you may find it helpful, now or in the future.

Support groups: Other groups may offer chances to meet people in similar situations, such as through a hospice or local carer's organisation. Ask your local authority, or health and social care trust in Northern Ireland, for groups in your area.



“I think being able to share what I went through, with people who are in that situation now helps them feel less isolated.”

Voluntary organisations: Many charity organisations offer bereavement support. To help you begin your search, see *Useful organisations* at the end of this booklet.

Online communities: You may already be part of an online community, such as the MND Association online forum, which includes a section on bereavement:

<https://forum.mndassociation.org/living-with-bereavement>

Many people continue to access this type of support after bereavement, as it enables discussion with others in similar situations. Some people prefer to simply view posts, as it can be reassuring to know others share similar experiences and feelings.

Financial support during bereavement

You may have stopped working to provide care. Benefits like Carer's Allowance also stop when your caring role ends. This can cause worries about money and finances.

MND Association Support Grants

The MND Association provides grants for carers and young people affected by MND. These grants can also be claimed up to 12 months after the person with MND has died.

For more information, see:

www.mndassociation.org/financialsupport

or contact our Support Services team:

Telephone: **0808 802 6262**

Email: **support.services@mndassociation.org**

Benefits

Contact the MND Association Benefits Advice Service, or an independent benefits adviser, who can check if you qualify for any payments including:

Funeral Expenses Payment: You may be entitled to help with funeral expenses if you receive certain benefits.

Bereavement Support Payment: You may be entitled to this payment if you're under state pension age and your spouse or civil partner, who paid National Insurance contributions, has died.

For details, search for the relevant benefit or payment at:

www.gov.uk or in Northern Ireland at: **www.nidirect.gov.uk**

See Further information in section 7: How do I find out more? for contact details of our free Benefits Advice Service.

4: How can I adjust when bereaved?

“For most of us, bereavement will be the most distressing experience we will ever face...we have to cope and adjust to living in a world which is irreversibly changed. We may have to let go of some dreams built up and shared with the person who has died. The length of time it will take a person to accept the death of someone close and move forward is varied and will be unique to the mourner.”

Cruse Bereavement Care

As time passes, emotions that were once overwhelming usually become manageable, but this can take a while.

If you were a carer you may:

- feel a lack of purpose when your caring role stops
- worry about whether or not to return to work, if providing support meant you had to leave employment
- find the life you had before no longer feels like your life now
- realise your social support network has changed, want to try different activities or meet new people.

Make any decisions and changes when they feel right for you.

If you were the person's main unpaid carer, the skills gained from this may help you adapt to life now better than you expect. Supporting someone during difficult times can deepen your understanding of yourself and your abilities. This can encourage personal growth and a different outlook.

“Post-traumatic growth does not necessarily mean that the person will be entirely free of the memories of what has happened to them, the grief they experience or other forms of distress - but that they live their lives more meaningfully in the light of what happened.”

Professor Stephen Joseph, University of Nottingham

Life will never be the same, but it's unlikely your loved one would want you to grieve forever. Try to give yourself permission to adjust, there is no need to feel guilty about adapting to life without the person who has died.

If you stopped working, returning can feel daunting. However, you are likely to have gained a range of new skills, such as learning to cope under pressure, making complex arrangements, acting as an advocate or facing the social care and benefits systems.

We provide information on returning to work in section 10 of our guide, *Caring and MND: support for you*. See *Further information in section 7: How do I find out more?* for details about our resources.

Moving forwards



“I don't believe in the word healing, you are changed forever.”

Coming to terms with the death does not mean you've forgotten the person, or don't feel love for them anymore. It simply means allowing yourself to move forwards. Grief is part of your life, but you can continue to adjust and grow around it.



Special occasions, birthdays and celebrations will feel difficult at first, but these become easier to cope with. These events gradually become opportunities for you and others to remember the person. Finding special ways to celebrate happy memories can help, such as:

- creating photo albums or memory boxes. This activity can also be helpful for children and young people (see also section 5: *How do I support children and young people who are grieving?*)
- viewing video or digital memories the person may have left for family and friends
- planting a special tree or plant in the garden.

Your experience of bereavement will not be the same as anyone else's, and the time you need to adjust will be entirely personal. It is important to do whatever feels right for you. When you feel ready, you may wish to take up new interests or reconnect with people you lost contact with.



“I had to make new friends. This took a couple of years but I joined a swimming club, took a year's course on gardening – all things I didn't have time for before.”

If you need emotional support or practical guidance, contact our MND Connect helpline, they can also direct you to other services.

See *Further information in section 7: How do I find out more?* for contact details.

5: How do I support children or young people who are grieving?

MND can be distressing for the whole family, and the death of someone close can have a big impact on children and young people's lives. They may need extra support when bereaved, which can feel difficult to manage when you're grieving yourself.

Our information for children, young people and families can help, both during the illness and after the death.

See Further information in section 7: How do I find out more? for details about our resources.

We also provide support grants for children and young people affected by MND, to fund items or experiences. These can be claimed up to 12 months after the person with MND has died.

See Financial support during bereavement in section 3: Who can support me?

If the child or young person is experiencing intense and difficult emotions that do not ease many months after the death, contact their GP. They may refer them to a bereavement counsellor, or grief support worker from a bereavement support organisation. There is often a waiting list.

We work with the national charity Barnado's, to offer children and young people affected by MND swift access to counselling. Contact **cyp@mndassociation.org** or our helpline MND Connect for more detail.

See Further information in section 7: How do I find out more? for MND Connect contact details and other organisations who may be able to help.

Communication

It is natural to want to protect children from upset, and talking about death is not easy. However, talking about death and grief can be as helpful for young people as it is for adults.

Without clear communication, children may feel isolated and use their imagination to fill the gaps. They may even blame themselves or become frightened. Young people may feel they can't openly express their grief if they want to protect you or other family members from further upset. Encouraging them to have conversations about how they feel can help.

How children and young people react to a death can vary with age. Age appropriate communication can be very helpful during bereavement:

Children react differently: Children grieve in a very different way to adults, which can be hard to understand. They tend to take in information in bite-sized pieces, then appear to carry on with what they were doing or playing with. They may talk repeatedly about what has happened, or ask questions at inappropriate times. It can seem as if they don't care, but children have different ways of dealing with things.

Understanding: Use language the child or young person understands and include why something is happening. For example, explaining that MND affects the muscles may help children understand why the person grew physically weaker.

Honesty: Being open even when it's difficult builds trust, both during the illness and into bereavement. It helps young people feel included and less isolated. Answer their questions truthfully, but appropriate for their age and understanding. Avoiding answers may confuse them and cause worries later on.

Participation: Children and young people need to feel involved, and that they can say and do things as part of their own grieving. This can help them find ways to manage their feelings. For example, creating a memory book or box can help them talk and ask questions.

Use our free *Memory Box* project to help young people capture memories for the future. Email cyp@mndassociation.org to request a *Memory Box*.

Involving others: Tell those directly involved with the child or young person about the death as soon as possible, such as family members, teachers or trusted family friends. This can help them support the child or young person too.

Find resources on supporting children and young people affected by MND in our hub: www.mndassociation.org/cyp, and use our *MND Buddies* hub to find activities and ways to discuss MND with young children: www.mndbuddies.org

Should they go to the funeral?

There may be religious, cultural or family reasons to either include or not include children or young people at a funeral. However, where possible, it can be helpful to let them be involved in the decision. You can help them decide what feels right for them by explaining what will happen on the day.

Getting together with family and friends to say goodbye can help underline the finality of death. This can be as helpful for young people as it is for adults.



“I kept asking my granddaughter what she wanted or would like for her gran, so she had her say as well... she played a part in her gran’s living in this world and in her leaving for the next.”

However, some children and young people may decide not to go to the funeral. They may feel self-conscious or scared about how they, or others will react. Everyone copes differently. They may feel more comfortable going to the grave or memorial at a later date.

Whether they attend the funeral or not, there are other ways children and young people can be involved. For example, they may want to create something that can be read or seen at the funeral, help choose the music or have something personal placed in the coffin.



“I made a card and letter to go in her coffin. I’m glad I did it and happy because I feel like it will always be with her.”

When should they return to school?

There is no set amount of time for a young person to feel ready to return to school. It will depend on their outlook, age, personality and relationship with the person who died, as well as their support network at school.

Some children want to go back to school immediately for a sense of ‘normality’ or structure, while others will need more time.

It is important to communicate with a trusted teacher, tutor or other member of staff at school or college during each stage of MND, including when the person dies. This can support the young person’s return.

It may help to include the child or young person in these conversations, so they can talk about:

- any concerns they have about returning, so that these can be dealt with
- if they want their classmates or friends to know about the death and, if so, who will tell them
- what may help if they begin to feel overwhelmed.



6: What needs to be done when someone dies?

Only do what you have to in the early days. Try not to make lots of big decisions too quickly, as your views may change over time.

However, there are certain legal, financial and practical tasks that must be completed after a death. These can provide a sense of purpose during a difficult time, but may also be stressful. Ask for support if needed.

Three things that must be done as soon as possible:

- 1** A medical certificate for cause of death will need to be issued by either the medical examiner or GP depending on if the person died at home or in hospital. If the death was expected they will discuss what they are going to put on the certificate and ask if you have any concerns. If you are arranging a cremation, an additional certificate may need to be signed by a doctor not involved in the person's care.
- 2** Make an appointment to register the death within five days, you will be able to buy death certificates and receive written authorisation to arrange a funeral. It is law that you must register the person's death.
- 3** Arrange the funeral, either through a funeral director or make the arrangements yourself, if wished. In some faiths, the body must be buried within 24 hours of death.

The government advises that these three tasks should take priority. You can find out more at: www.gov.uk/after-a-death



“I paid for more certified copies of the death certificate than I thought I would need. It’s cheaper to get them at the time of registration.”

At this time, family and friends usually want to help, so let them know what you would find most helpful. Support with preparing meals or cleaning may help you focus on other things. You may wish to use section 8: *My pages* at the end of this booklet to keep a ‘to do’ list, and track who is helping with each task.

What else do I need to do?

Telling people the person has died: Contacting one or two people at a time may be easier than tackling a long list all at once. If you find it overwhelming, a friend or family member may be able to help.

Benefits and entitlements: If the person received financial support from central or local government, or you received carer support such as Carer’s Allowance, you need to inform the relevant departments of the person’s death.

In some areas of England and Wales, the Tell Us Once service from GOV.UK lets you inform all services in one go. See more at: **www.gov.uk/tell-us-once**. You can also contact the DWP Bereavement Service on **0800 151 2012** to report a death and find out what financial support may be available, as well as request pension updates if it is your spouse or civil partner who has died.

In Northern Ireland, contact The Bereavement Service to report a death to the Department for Communities:
www.nidirect.gov.uk/contacts/bereavement-service



“I found ‘Tell Us Once’ a great help as it covered all his pensions and benefits immediately and saved me and his eldest son a lot of trouble and worry.”

Notify banks and building societies: Tell the person's bank or building society about the death as soon as you can. Most of the person's affairs can be sorted later. As long as they have been notified of the death, banks and building societies are aware that dealing with the person's estate can sometimes take longer than a year. There are organisations who can guide you. See *Useful organisations* in section 7: *How do I find out more?* for details.

Power of Attorney: If you held power of attorney for the person, were a deputy appointed by the Court of Protection or were an authorised user on any financial accounts, these authorities end when the person dies. This means you will no longer be able to access the person's bank account.

Dealing with the person's money and belongings (estate): You may need legal help to sort out the person's estate after their death, which costs money. If there is a will, the named executor takes responsibility. If there isn't a will, the government decides how the estate is inherited, but usually the partner or a family member takes responsibility for managing the process. Find out more about dealing with the estate at: www.gov.uk/wills-probate-inheritance, or in Northern Ireland search for 'applying for probate' at: www.nidirect.gov.uk



Equipment: You may need to return or dispose of equipment such as a riser recliner chair used by the person with MND. This may be helpful, allowing you to remember how they were before their diagnosis. However, if it's distressing to see equipment go that reminds you of the person, let the provider know. They may be able to leave it with you a little longer.



“I knew I had to get the house back to the way it was before all the ceiling hoists, ramps, equipment storage etc. and this gave me something to focus on.”

Professional support: Any previous support from health and social care professionals stops if related to care for the person with MND. This can feel isolating, especially if you built relationships with them. If you are being supported by palliative care professionals, you may find it helpful to talk to them about all that you achieved as a carer. As the demands of caring may have left you exhausted and at risk of illness, it is also worth getting a health check from your GP. This can also provide a bridge between professional help before bereavement and adjusting to life after.



“My GP was fantastic. I saw him every month for six months after my son died, just to talk about how I was.”

Our helpline MND Connect: The team can provide emotional and practical support. See *Further information* in section 7: *How do I find out more?* for contact details.



“I found ringing up organisations such as utility companies not as bad an experience as I'd imagined.”

What happens to online accounts?

Online social media accounts, memberships, websites, blogs, and any other online resources owned by the person who died are known as their 'digital legacy'.

With social media accounts, you can choose to:

- **do nothing:** this enables people to continue viewing and posting to the person's account as before, but nobody can regulate that content
- **memorialise the account:** this enables existing contacts to post tributes, and prevents it being logged into
- **close the account:** this deletes the person's account. This could impact on friends and family who may wish to look back at posts, images or videos.



“We spoke about his social media page and he wanted it to be kept open. There are so many memories on here and I can look back at them and remember the good times.”

Go to the 'support' or 'help' section of the social media website to find out more about closing or memorialising an account. You may need to provide proof of death and your identity and relationship with the person.

For more information, visit The Digital Legacy Association at:
<https://digitallegacyassociation.org/for-the-public>

Arranging the funeral

Some people with MND plan their own funeral, but certain arrangements still have to be made after the death.



“He planned his own funeral. He knew exactly what he wanted, right down to the details of the music, prose and pictures. Because he was so open about it, it was easier for us to arrange. It was a beautiful funeral.”

You or someone close to the person can manage the funeral, or a funeral director can guide and co-ordinate services. Some faiths and beliefs have rituals that must be observed. You may need help from a funeral specialist or faith leader. Non-religious ceremonies and humanist funerals usually avoid all references to a god or afterlife.



“He had a humanist funeral and everyone participated and chose music... It was a beautiful day and we all walked across the common to the cemetery. Even the dog was there, who’d sat next to him in the chair when he was ill. We all remember it as a happy day – he would have been happy with it.”

You can find more about funeral planning in section 10 of our guide: *End of life*. See *Further information* in section 7: *How do I find out more?* for how to download or order.

Attending the funeral provides a way to say a final goodbye and is a public acceptance of what has happened. This can help those affected start to adjust to life without the person.

Some people might not be able to attend for practical reasons. Others may prefer not to attend. Everyone is different, and will find a way to accept the finality of the death that feels right for them.



“As he had travelled a lot, the funeral director found a way to stream the service online. This meant his friends from around the world who couldn’t make the journey to the UK could still be a part of it.”

The person may have left directions about flowers or collections for a nominated charity if they had made plans for their own funeral. This can be managed by the funeral director, if you have one.

A gathering after the funeral may provide a chance for people who knew the person to come together to remember them. This can be an opportunity to reconnect with your wider group of friends and family.



7: How do I find out more?

We do not endorse these organisations, but they may help you search for services or information. Contact details may change between revisions. Our MND Connect helpline can also help you find services, (see *Further information* in this section for contact details). Find more links at: **www.mndassociation.org/usefulorgs**

Support for bereaved adults

AtALoss.org

Search for a bereavement support organisation near you.

Website: **www.ataloss.org**

Bereavement Advice Centre

Advice on legal and practical steps after someone's death.

Telephone: **0800 634 9494**

Website: **www.bereavementadvice.org**

The Bereavement Service (Northern Ireland)

When informed of a death, they tell all offices paying benefits to the person and can check entitlement to bereavement benefits.

Telephone: **0800 085 2463**

Website: **www.nidirect.gov.uk/articles/bereavement-service**

The Compassionate Friends

Support for people after the death of a child of any age.

Telephone: **0345 123 2304**

Email: **helpline@tcf.org.uk**

Website: **www.tcf.org.uk**

Cruse Bereavement Support

Free and confidential bereavement support for adults, young people and children. They have a national helpline and local services provided by trained volunteers.

Telephone: **0808 808 1677**

Website: **www.cruse.org.uk**

Digital Legacy Association

How to manage a person's online presence after they die.

Telephone: **020 3286 6812**

Website: **<https://digitallegacyassociation.org>**

Down to Earth

Free guidance on affordable and appropriate funerals, and possible government support or charitable funds.

Telephone: **020 8983 5055**

Email: **downtoearth@qsa.org.uk**

Website: **<https://quakersocialaction.org.uk/we-can-help/helping-funerals/down-earth>**

The Good Grief Trust

Online grief support and information and lists of local services.

Website: **www.thegoodgrieftrust.org**

GOV.UK

Online government information about benefits and support in England and Wales.

Website: **www.gov.uk**

Mind

Support for mental health issues, and emotions when bereaved.

Telephone: **0300 123 3393**

Email: **info@mind.org.uk**

Website: **www.mind.org.uk**

MND Scotland

MND information, care and research for Scotland.

Telephone: **141 332 3903**

Email: **info@mndscotland.org.uk**

Website: **www.mndscotland.org.uk**

NI Direct (Northern Ireland)

Government information about health and social care.

Email: **through the website contact page**

Website: **www.nidirect.gov.uk**

Widowed and Young (WAY)

Support groups for bereaved partners across the UK aged under 50.

Email: **through the website contact page**

Website: **www.widowedandyoung.org.uk**

Support for bereaved children and young people

Child Bereavement UK

Bereavement support for children and young people.

Telephone: **0800 0288 840**

Email: **helpline@childbereavementuk.org**

Website: **www.childbereavementuk.org**

Childline

24-hour support for children and young people in distress.

Telephone: **0800 1111**

Email: **through website and confidential login**

Website: **www.childline.org.uk**

Childhood Bereavement Network

Guidance and lists of services for bereaved children.

Email: **through website contact page**

Website: **www.childhoodbereavementnetwork.org.uk**

The Good Grief Trust

Online grief support, with blogs, videos and playlists.

Email: hello@thegoodgrieftrust.org

Website: [www.thegoodgrieftrust.org/ find-support/for-young-people](http://www.thegoodgrieftrust.org/find-support/for-young-people)

Grief Encounter

Support for bereaved children and their families.

Telephone: **0808 802 0111**

Email: griefftalk@griefencounter.org.uk

Website: www.griefencounter.org.uk

Hope Again

Cruse Bereavement Care's website for bereaved young people.

Telephone: **0808 808 1677**

Email: opeagain@cruse.org.uk

Website: <https://hopeagain.org.uk>

Hope Support Services

Support for young people when a close family member is diagnosed with a life-threatening illness.

Telephone: **01989 566317**

Email: help@hopesupport.org.uk

Website: www.hopesupport.org.uk

Winston's Wish

Support for bereaved children, young people and parents.

Telephone: **0808 802 0021**

Email: ask@winstonwish.org.uk

Website: www.winstonswish.org.uk

Young Minds

Support for young people's mental wellbeing. Website includes ways to manage difficult emotions.

Website: <https://youngminds.org.uk>

Acknowledgements

Thank you to our many contributors who have cared for someone with MND and kindly offered their valuable insight and review of this booklet.

And thank you to the following for their kind assistance in the development or revision of this booklet:

Anjana Vaja, Cultural Support Officer, LOROS, Leicester

Gwyneth Peden, Trust Bereavement Co-ordinator, Northern Health and Social Care Trust, Northern Ireland

Dr Amanda Mobley, Consultant Clinical Neuropsychologist, Worcestershire Health and Care NHS Trust

Alison Morton, Palliative and End of Life Care Lead, Dorset County Hospital NHS Foundation Trust

References

References used to support this information are available on request from: **infofeedback@mndassociation.org**

Or write to:

Information feedback, MND Association

Francis Crick House (2nd Floor), 6 Summerhouse Road Moulton Park, Northampton NN3 6BJ

Further information

You may find some of our other publications helpful.

Caring and MND: support for you

To help you look after your own wellbeing as a carer.

End of life: a guide for people with motor neurone disease

To help with end of life decisions and getting affairs in order.

Telling people about MND

To help people with and affected by MND open difficult conversations with family, children, friends, colleagues and professionals.

Emotional and psychological support

To help people with and affected by MND find support.

Supporting a child or young person close to someone with MND

To help professionals who provide support.

When someone close has MND: a workbook for children aged four to ten

To help a trusted adult communicate with younger children about MND, including activities for the child.

Why is everything changing?

A storybook for young children about families affected by MND.

MND Buddies

An online activity hub to help young children affected by MND:

www.mndbuddies.org

So what is MND anyway?

A guide and web app to support young people in the family.

For full details about our resources for children, young people, and parents or guardians, see: **www.mndassociation.org/cyp**

Search easily for information by need using our ***care information finder***: **www.mndassociation.org/careinfofinder**

You can download most of our publications from our website at:

www.mndassociation.org/publications

or order in print from the MND Connect team, who can provide additional information and support:

MND Connect

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Young people can also contact our helpline, MND Young Connect:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

MND Association website and online forum

Our forum includes a section for people bereaved by MND. You can view the forum without signing up if you prefer.

Website: **www.mndassociation.org**

Bereavement web page: **www.mndassociation.org/bereavement**

Forum: **<https://forum.mndassociation.org>**

MND Association Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance.

Tribute Funds

Tribute funds create a fundraising legacy in memory of a loved one.

Email: **tributefunds@mndassociation.org**

Website: **www.mndassociation.org/tribute**

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. You can feedback on this booklet using an online form at: **www.smartsurvey.co.uk/s/BereavementBooklet**

Or request a paper version by email:

infofeedback@mndassociation.org

Or you can share your thoughts with us by post, write to:

MND Association, Francis Crick House (2nd Floor)

6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ

8: My Pages

To be used in any way you wish



Created: April 2022
Next review: April 2025
Version: 1



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