Bereavement support

Information for people with or affected by motor neurone disease

This information sheet has been produced to help you cope with the emotions you may feel after a loved one’s death, whether the death was sudden or expected. It has been written with particular regard for families affected by motor neurone disease (MND).

The content includes the following sections:

1: When does grieving begin?
2: What can I expect during bereavement?
3: What do I need to do when someone dies?
4: How do I communicate with children or young people who may be grieving?
5: How can I adjust to life with bereavement?
6: How do I find out more?

This symbol is used to highlight our other publications. To find out how to access these, see Further information at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND, unless otherwise attributed.

The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis
“For most of us, bereavement will be the most distressing experience we will ever face. Grief is what we feel when somebody we are close to dies. Everyone experiences grief differently…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

1: When does grieving begin?

Bereavement can feel very distressing and isolating, and when a loved one is diagnosed with an incurable and life-shortening illness like MND, the grieving process usually begins in advance of the bereavement. This may impact on your wellbeing before and after the person has died.

Anticipation of loss

If someone close to you has died from MND, it is likely that you were involved in their care. The progressive nature of the condition means that you probably had to provide increasing support during the course of the disease and are likely to have experienced multiple and difficult emotions through this period.

You may have felt:

- a deepening separation and a sense of impending dread
- feelings of grief and sadness over a long period of time
- aware that the person with MND was also grieving as they faced their own loss.

This is known as anticipatory grief and, combined with the exhaustion of the caring role, it can be very draining.

The pathway through the disease is complex and individual, but impairment does increase. You may have felt as if you were gradually losing the person throughout the progression.

Sometimes a life-shortening condition can provide a time for reflection, making up for past quarrels and letting each other know how you feel. However, you may have:

- lived in hope that the diagnosis could be wrong
- wished that a miracle cure would be found in time
- felt that to accept the diagnosis would mean giving up on your loved one.
How you responded then, and after the bereavement, will be very personal to you.

Anticipatory grief does not usually prevent grief after the person dies, but it can help you to prepare for the end of your loved one’s life. The ups and downs of a prolonged illness, and the losses you experienced along the way, may have helped you to develop ways to cope.

The impact of anticipatory grief

Anticipatory grief can take its toll on your health and wellbeing. Having to then deal with bereavement and the aftermath can be very tough.

“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 the inevitable telephone calls and arranging a funeral can be very stressful.”

You may wish to consider asking your GP for a health check-up following bereavement, particularly if you were the main carer. It may be valuable to consider your wellbeing in this way, as you may be exhausted physically and emotionally.

It is unlikely that your GP will refer you to specialist help or counselling immediately after a death, as a period of grief and mourning is to be expected, but they can check your blood pressure, general health, talk through any stress that you may be feeling and help with problems such as finding it difficult to sleep.

“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

If you experience physical symptoms that cause you concern, especially if they persist, always get them checked by your GP. They will either be able to reassure you or take appropriate action.

2: What can I expect during bereavement?

The range of intense emotions can be confusing and you may worry that your grief is not normal. Yet there is no ‘normal’ as everyone will have their own response to their unique loss.

How you grieve will depend on your circumstances and your emotional state. It is important to realise that grief can encompass many feelings and may feel irrational, but your grief is personal and there is no right or wrong way to experience it.
What should I expect to feel?

In the first few days and weeks following a death, you may experience many emotions including numbness, disbelief, anger, guilt and pain. You may be too shocked to feel anything at first and a delayed reaction is very common.

Once the initial shock has passed, you may have very powerful emotions. You may feel:

- high and excitable, or very tearful
- that you do not care if you live or die
- that you have lost the person you love and the loss is all consuming
- that you cannot think about anything else
- isolated and alone
- angry with yourself, the person who has died and anyone and everyone who was involved.

You may also feel a sense of relief, which can be confusing, but this is common where a loved one has been through a difficult illness like MND. This is particularly true if you have been the main carer. Not only is the person you cared for now released from the challenges of the disease, but you have been released from the increasing and sometimes overwhelming demands of the caring role.

While it is not abnormal to feel relief after the death, it can lead to feelings of guilt. If this is the case, take time to acknowledge the support and care you have given and allow yourself time to recover physically. In time, a sense of balance usually returns.

Many people release their feelings through crying. This is a natural reaction to bereavement and provides an outlet for the tension that can build with grief. However, it is not the only response and how you react is likely to be influenced by your:

**Beliefs:** where your opinions, moral viewpoint, faith or values influence the way you react.

**Cultural and family background:** where your upbringing, way of life and social values have helped to shape your responses.

**Personality:** where your own personal preferences and sense of self have an impact.

**Relationship with the person who died:** which will affect the way you feel about their death.

**Relationship with others who are close:** where the feelings of other people may cause you to adapt your own expression of grief, for example where young children are involved.
If you were raised to contain your feelings when you were young, then you may not feel comfortable expressing your grief in public. If openly expressing your emotions has always been encouraged, then you may feel the reverse. You should try not to worry about the ‘correct’ way to show your feelings. Allow yourself to grieve in the manner that best helps you to cope.

Overwhelming sadness usually lifts in time, but for some people this can continue. If you feel concerned that your grief is not getting any easier to deal with and this makes it difficult to cope with everyday life, talk to your GP for help and advice.

Are these feelings normal?

It is important to realise that all of these reactions are perfectly normal. You may experience ongoing feelings of loneliness, sadness and longing, but all grief is unique and personal. These feelings are likely to adapt. This adjustment cannot be rushed and will vary from one person to another.

You may hear people refer to the ‘stages of bereavement’, such as denial, anger, bargaining, depression and acceptance. These stages may indeed be experienced by those who have been bereaved, or by those who have been given a life-shortening diagnosis, but they are not absolute. Not everyone will experience every stage, or in the same order or for the same length of time. There are other emotions and possible stages that could be experienced.

In other words, there is no fixed pattern and you need to deal with bereavement in your own way.

Were the dying person’s feelings normal?

You may ask this question if the person appeared to have a change of personality, which can happen for some people with MND.

The fear of dying may have made them depressed and they could have taken their frustration out on you. Some people with MND may also experience varying degrees of cognitive change, where thinking, planning and reasoning become more difficult, but this does not usually have a major impact on everyday life.

In a small minority of cases, a type of dementia called frontotemporal dementia (FTD) may develop, which can be very hard to deal with. If your loved one displayed extreme personality changes, aggression or severe problems with reasoning, you may be left feeling particularly confused and angry.

“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.”
If you feel you need to talk about these feelings and how this has affected you, do speak to your GP, your wider health and social care team or our helpline, MND Connect. See Further information in section 6: How do I find out more? for MND Connect contact details. There is help available and you may need support to deal with the impact of the illness and the death.

How do I cope with these emotions?

Grief is the collective name given to our natural responses after the death of someone close. This can affect you emotionally, physically, spiritually and socially. The overriding feelings are usually pain and loss.

You may find you have mood swings, such as alternating between crying and being angry, which can be very confusing and may leave you feeling drained. It is also possible to feel more than one emotion at a time, for example, anger and guilt. This is all part of the grieving process and will gradually become calmer.

Experiencing strong emotions during bereavement is natural and to be expected, but can become particularly distressing if you feel overwhelmed. Asking how to cope with difficult emotions is another way of asking ‘How do I manage them?’ or ‘How do I regain a sense of control?’.

If you do begin to feel overwhelmed, identifying your emotions can help you work out ways to cope with your feelings:

**Shock:** Sometimes shock can cause a physical reaction, including feelings of nausea or shaking. You may experience difficulty in sleeping, heart palpitations or physical exhaustion. You may also be more susceptible to illness or infection.

You may feel shock even if the death was anticipated and it can take a while to overcome this. Be kind and look after yourself. Don’t take on too much while grieving. These powerful emotions will eventually subside, although you may still be left with intense longing for your loved one.

**Anxiety/panic:** Occasionally anxiety or feelings of panic may overwhelm you. You may worry that something bad will happen to someone else you love. You are likely to feel more vulnerable after a death, as if your whole world has been turned upside down and your thoughts and emotions are all over the place. Although this is uncomfortable, it is not uncommon and these feelings will become less extreme with time.

If these feelings do not subside, or you feel the intensity is worsening, speak to your GP who may be able to help by referring you to a bereavement counsellor (or a grief support worker from a bereavement support organisation).

**Longing/loneliness:** You may alternate between feeling bewildered or very weepy. Painful yearning for the deceased can be especially acute in the immediate period after their loss.
You may also feel grief for unfulfilled dreams and plans for the future, which you had hoped to share with them. You have lost not only the person, but love, intimacy and companionship. These feelings may make you feel that life has lost its meaning and there is nothing left.

Grief can make you feel very alone, you feel as if no one can possibly understand what you are going through, and you wonder why it had to happen to you. Although it may take time, social contacts are usually renewed and links to other people become stronger again.

**Regret:** You may ask yourself if the person that died knew how much you loved them. This can be very intense and these thoughts may happen repeatedly. You may wish you had said certain things or wonder what more you could have done, or feel that you should have done things differently. You may go over and over events leading to the death, wishing you could go back to make it better. You may have longed for the process to be over, especially if you were the carer. A long illness can be exhausting and your emotions were being pulled apart. Don’t feel guilty, you are only human.

Regret can be especially acute if the death was unexpected or not as peaceful as hoped. It is unlikely that your loved one would want you to think this way, but because they are so important to you, the questions remain.

While regret can be difficult to admit to others, talking about it can help. You cannot get the answer you need from the person who has died, but you can share your feelings with people who can add perspective (see later heading, *Talking about what has happened*). Family and friends for example, who knew the person, or a bereavement counsellor (or grief support worker from a bereavement support organisation), who can help you work through any particularly distressing thoughts.

**Anger:** You may feel anger against the world, where other people are still having fun and getting on with their life, while you are grieving. You may feel angry at being left alone or because other people don’t seem to understand how you are feeling. Your grief can make you despair of ever feeling positive about your life again.

If it helps, take your anger out in a way that does not hurt anyone, shout, scream, exercise or dig the garden. Venting your anger in a physical way can sometimes help to reduce destructive feelings of anger.

**Confusion:** Some people report that although they accept their loved one has died they can still sense their presence, or hear their loved one’s voice or footsteps. The person who has died may appear in dreams, giving the illusion they are still with you or looking after you. This can be very comforting for someone newly bereaved, so try not to be worried by this. It is not unusual, especially in the early days.

Don’t be too hard on yourself, all of these reactions are normal and understandable. No one has the gift of hindsight or the ability to predict the future. It is important that people around you realise that you need understanding, support and time to work through your grief.
Is it okay to talk to people about what has happened?

Talking to people who are close enough to understand why you feel the way you do is important. While this is unlikely to resolve your feelings immediately, it can provide release and gradually help you to come to terms with the death.

You may prefer not to talk about things and to grieve on your own, without the worry of breaking down in front of someone else. Your grief is personal and you have a right to keep it private, but try not to bottle things up too much. This could have repercussions for your health and wellbeing later on. Some people find writing down their thoughts in the form of a diary or letter can be helpful as an outlet for how they feel.

If you do wish to talk to someone, it can feel difficult if:

• you’re concerned about how the bereavement is affecting other people’s feelings
• family and friends change the subject or avoid it for fear of upsetting you
• people feel at a loss and don’t know what to say.

Gently exploring this is worthwhile, as others often wish they could be more open. Sometimes they just need to know that you would welcome the chance to talk about what has happened.

You may feel upset if you cannot freely discuss the person who has died, as this helps to keep their memory alive. You may need to seek out those who do feel able to talk or you may wish to make use of a support group, a counsellor or a helpline (such as MND Connect – see Further information in section 6: How do I find out more? for details). It can be helpful to talk to someone you don’t know, in confidence.

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

Grief may last a long time and may always be a part of how you feel. Yet for most of us, adjustment means that we can gradually accept these emotions, which usually become less intense. This helps you to adapt to routines and wider social contact again.

It is common to feel sadness at special events, because the person you loved cannot be with you, but for some people the intense period of mourning feels as though it will never stop. Mourning the death of someone close is normal, but if the emotions are all consuming and persistent, you may find it difficult to manage daily tasks or other relationships in your life.

If this disrupts your life to the extent that you cannot function normally, then it may be helpful to seek support. If left untreated, complicated grief may cause emotional trauma and even serious illness.
If you still find it difficult to manage everyday activities several weeks after the bereavement, such as getting washed and dressed, talk to your GP about referral for specialist help or counselling.

Please bear in mind that referral is unlikely to happen in the first couple of months unless there is a severe need, but it is worth making the enquiry if you need extra support. There may be a waiting list, but it can feel positive to take this step and know that help will become available.

If the waiting list is long, you may wish to consider paying privately for counselling, but take advice from your GP about how to seek qualified help.

**Will the grief return at a later date?**

You may experience a recurrence of grief months or even years after the event. Certain situations, songs, birthdays or anniversaries can all trigger emotional responses that could feel overwhelming again. This might be momentary or last for days.

This helps to remind us of the love we felt for the deceased and that their life was very precious to us. It does not usually mean that you are starting the grief cycle all over again. Although these waves of grief can be intensely powerful, they usually subside and your feelings will become manageable again in time.

Again, seek help if you experience this type of episode and the feelings do not get better.

**3: What do I need to do when someone dies?**

Following the death, there are legal, financial and practical tasks that need to be carried out. These can be comforting, providing a sense of purpose during a confusing and emotional period.

However, it may be stressful if you find it difficult to focus during the shock of what has happened. Dealing with registrars, banks, legal professionals and insurance companies can feel very bewildering at this time.

You may need practical help in the weeks following the death of someone close. At this time, family and friends usually want to do something, but don’t always know what you need. If someone offers support, let them know which tasks would be helpful.

Do not be embarrassed to ask for help with preparing meals or cleaning the house if that is what you need most.
There are three immediate things you must do when someone dies:

1. Get a medical certificate of cause of death from the doctor who was most recently looking after the person who died (your GP, in the hospice or in the hospital, as appropriate).

2. Make an appointment to register the death within 5 days, when you will be able to buy death certificates. You will also be given the documents you need to authorise the arrangement of the funeral.

3. Arrange the funeral through a funeral director or, if you wish, you can make the arrangements yourself.

The government advises that these three tasks should take priority, but you can find out more from their online service GOV.UK, at [www.gov.uk/after-a-death](http://www.gov.uk/after-a-death)

Most of the sorting out of the person's affairs can be done later, but it is a good idea to notify banks and building societies quickly to help prevent identity fraud. There are organisations who can guide you through these processes, see *Useful organisations* in section 6: *How do I find out more?* for details.

The following will also need to be considered:

**Power of Attorney:** If you have held a Power of Attorney for the person who died, were a deputy appointed by the Court of Protection or were an authorised user on any financial accounts, you need to be aware that all of these authorities cease at the moment of death. If there is a will, the executor(s) now take responsibility for practical matters of money or property and if no will exists, the personal representative of the deceased (usually their partner or a member of the family) should do this.

**Dealing with the estate (money and belongings):** Seek advice from someone with probate expertise if you need guidance on how to deal with the person’s estate. The formal processes are similar whether or not there is a will, but there are major differences in how the estate is distributed.

**Benefits:** If the person who died received benefits, don’t forget to cancel these with the provider and if you were the main carer, you may also need to cancel benefits such as Carer’s Allowance. If the Tell Us Once service is offered when you register the death, this will notify all central and local government departments to avoid you having to call them individually.

You can find out more details on the government website: [www.gov.uk/tell-us-once.](http://www.gov.uk/tell-us-once.)

**Major decisions:** Only do what is necessary and essential in the early days. Try not to make major decisions or changes too quickly, as your wishes may change over time. For example, you may regret throwing away everything that reminds you of the person who died. Provided they have been notified of the death, banks and building societies are aware that dealing with an estate can take some months or even a year or more.
**Feeling overwhelmed:** If your task list feels daunting, break activities down into smaller steps. Cope with one step at a time and avoid placing too much pressure on yourself. For example, deal with just one drawer of the person’s clothes as a set activity, or phone one person rather than tackling a long list. Again, you may be able to ask someone to help with these steps. Assistance with basic tasks like laundry and shopping can often provide a welcome release, allowing you time to think about more complex decisions, or just to rest. It can help to keep a list of what needs doing and who is taking care of which arrangements.

**Equipment:** There may be various items of equipment that will need to be returned or disposed of, following the death of someone with MND. This can feel stressful on top of the emotional effects of bereavement. You may find it distressing to see the equipment go, as this can feel very final, but it might be calming to remove reminders of the disease, so that you can remember the person the way you want to.

**Professional support:** Much of the previous support from health and social care professionals will stop, as this was directly associated with the care and treatment of the person with MND. This can feel isolating at first.

“*When someone dies, no-one comes any more. The house is empty.*”

If you have talked to your GP or been referred for specialist support, it can provide a bridge between the period of professional help before the bereavement and adjusting to life without this contact.

If you have not sought this type of guidance, our helpline MND Connect can provide a listening ear and practical support at this time (see *Further information* at the end of this sheet for contact details). You may also find it helpful to contact your local branch or group of the MND Association. Where an Association visitor is available, they will usually continue to provide support during bereavement.

**Financial support during bereavement**

You may be entitled to certain benefits if you have been bereaved. Some of these benefits can be claimed up to 12 months after the person has died. Contact the MND Association Benefits Advice Service or another independent benefits adviser if you think you may be entitled to claim any of the following benefits. See *Further information* in section 6: *How do I find out more?* for contact details of our free Benefits Advice Service.

**Funeral Payment**

If you have a low income, receive certain benefits and need help to pay for a funeral you are arranging, you may be able to get a Funeral Payment. For more information, search for funeral payment at: [www.gov.uk](http://www.gov.uk) or if you live in Northern Ireland, at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)
**Bereavement Support Payment**

You may be entitled to Bereavement Support Payment if the person with MND died on or after 6 April 2017 and:

- you are under state pension age
- the person that died was your husband, wife or civil partner
- the person that died paid National Insurance contributions.

This is usually paid as an initial payment, followed by up to 18 monthly payments. It is not means tested or taxable. For more information and how to apply, search for bereavement support payment at: [www.gov.uk](http://www.gov.uk) or if you live in Northern Ireland, at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

**Bereavement Payment**

You may be entitled to Bereavement Payment if the person with MND died before 6 April 2017 and:

- you are under state pension age
- the person that died was your husband, wife or civil partner
- the person that died paid National Insurance contributions.

This is a tax free, one-off payment. It is not means tested or taxable. For more information, search for bereavement payment at: [www.gov.uk](http://www.gov.uk) or if you live in Northern Ireland, at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

**Bereavement Allowance**

You may be entitled to Bereavement Allowance if the person with MND died before 6 April 2017 and:

- you are aged between 45 and state pension age
- the person that died was your husband, wife or civil partner
- the person that died paid National Insurance contributions.

This benefit is a weekly payment. It is not means tested, but is taxable. For more information, search for bereavement allowance at: [www.gov.uk](http://www.gov.uk) or if you live in Northern Ireland, at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)
Widowed Parent’s Allowance

You may be entitled to Widowed Parent’s Allowance if the person with MND died before 6 April 2017 and:

- you are under state pension age
- you are responsible for at least one dependent child aged under 19
- you are claiming Child Benefit for at least one dependent child
- the person that died was your husband, wife or civil partner
- the person that died paid National Insurance contributions.

This benefit is a weekly payment. It is not means tested, but is taxable. For more information, search for widowed parent’s allowance at: www.gov.uk or if you live in Northern Ireland, at: www.nidirect.gov.uk

Attending the funeral

Some people with MND choose to make plans for their own funeral and may have found it comforting to contribute to the content. However, there will still be specific arrangements to make following the death. Funeral directors can take care of this for you and will provide detailed guidance.

For many, attending the funeral is helpful, because it provides a way to say goodbye and is a public acknowledgement of what has happened. This helps those affected by the death to begin to adjust to life without their loved one.

This can be especially helpful when someone has been ill for an extended period of time, where contact with their wider community of friends and colleagues may have been severely reduced.

You may also wish to arrange a specific memorial service or celebration of the life of your loved one.

“I carry the funeral sheet with me wherever I go. My good friend helped me to write and print it out, just exactly how I wanted it. In it, I said how she would have liked to be there and how we had laughed about that together.”

The funeral provides an opportunity for people to show their support and some faiths and beliefs will also have important rituals that must be observed. If specific rites need to be carried out, you may need to engage help from your particular community. This might require a funeral specialist or guidance regarding a religion or belief.

Civil ceremonies can be arranged, which focus on the specific preferences of those close to the person who died. These can include religious elements, such as hymns and prayers.
If a non-religious ceremony is required, a humanist funeral usually avoids 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.”

Some people might not be able to attend for practical reasons. Others may prefer not to attend, but they will find their own way of saying goodbye. Either approach helps people to accept the finality of their loved one’s death and to begin to face the future without them.

4: How do I communicate with children or young people who may be grieving?

Many people find it difficult to talk about death. This can feel worse where children are involved, as it is a natural desire to protect the young from distress. However, if they are left without clear explanations, they may use their imagination to fill the gaps. They may think that they are to blame or become frightened. To help you communicate with them about MND, we have developed information for children and young people about the disease see Further information in section 6: How do I find out more? for details.

You may find the following helpful:

**Children think differently:** Children grieve in a very different way to adults, which may be difficult to comprehend. Sometimes, it may seem as if they don’t appreciate the enormity of what is happening, or even care. This is not necessarily true, but it can feel bewildering.

Children tend to absorb information in bite size pieces, and then they resume playing or engaging with whatever they were doing before the conversation took place. This means that they may need to talk repeatedly about what has happened, which may have an impact on how you feel. They may ask questions about what has happened at random or even inappropriate times. This is all natural and just a child’s way of dealing with events.

**Comprehension:** When communicating sensitive matters to children, it is really important to use language that they understand. Words that we use to explain something can have a completely different meaning to a child. For example, a young child might interpret a ‘heart attack’ as someone actually attacking someone’s heart, but what they need to hear is that the heart became poorly. Where MND is concerned, it can help to explain that the disease affects the muscles, so that children understand why someone changed and grew weaker.
**Honesty:** Explaining what is happening during the course of the disease can be very helpful, so the child does not feel isolated. This also gives them an opportunity to be involved, and say and do the things they need to do, as part of their own grieving. This may help them to develop ways to cope. For example, creating a memory book or box with the person who is dying can be a great way for both to capture moments that will provide comfort to the child in the future.

When the person dies, any questions that the child asks should be answered as truthfully as possible for their age and level of understanding. Skirting around the issue may confuse and cause anxiety for the child later on.

People that are directly involved with the child should be told as soon as possible, so that they can offer support if needed, such as family members, teachers and family friends.

**Should young people go to the funeral?**

There may be religious, cultural or other family reasons not to include children or young people at a funeral. However, where possible, it can be beneficial to give young people a choice about whether they attend or not. You can help by explaining what will happen on the day, so they can decide what feels right for them.

Some may take comfort from attending the funeral, as it can help them to understand the finality of death. The opportunity to gather with family and friends to say goodbye can be very helpful for young people, in the same way that it is for adults.

“When her gran died we waited until we were all together and told my granddaughter. We were all upset and cried together. The next day the funeral director came round, again we were all together and 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 her gran’s living in this world and in her leaving for the next.”

Some children and young people may find it overwhelming and decide they don’t want to attend the funeral. This is not disrespectful to the person who has died, as everyone reacts and copes differently. A child or young person may feel more comfortable attending the grave or memorial at a later date, with a trusted adult or in a smaller group.

Whether they attend the funeral or not there are likely to be opportunities to get involved in some way. For example, a child or young person may want to create something that can be read or seen at the funeral, help to choose the music or have something personal placed in the coffin.
5: How do I adjust to life with bereavement?

As time passes, overwhelming emotions usually lessen and become more manageable. You may think constantly about your loved one and still wish you had them with you, but the intensity of your grief will usually start to fade. You will be able to cope more easily with everyday tasks and resume many aspects of your life.

If you provided lots of support, you may have been the main carer. Providing care to someone with MND can be complex and means you had to adapt to new ways of doing things. You may be surprised at how this helps you to find ways to cope after the person you were close to has died.

Despite the challenges of the caring role, you may feel a loss of purpose after bereavement. Your own sense of identity may have been affected, particularly if you were employed and left work to manage the care.

Reverting to the way you lived before becoming a carer may not be possible or feel appropriate anymore. You may begin to live life in a different way. In the longer term, you are likely to forge new interests and your social network may change.

Previous activities you enjoyed together with the person who died may no longer feel right for you now. Adjustment will take time, so try not to pressure yourself. Allow the changes, and the choices you make, to happen gradually.

Supporting someone during difficult times can deepen your understanding of yourself and your abilities. This can encourage personal growth and help you to develop new skills and a different outlook.

“… 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

Although life will never be the same as before the bereavement, you do not have to be miserable for the rest of your life. Your loved one would not want that. As you begin to acknowledge this, give yourself permission to change and not feel guilty about adapting to life without the person who has died.

Coming to terms with death does not mean that you’ve forgotten the person or don’t feel love for them anymore. It simply means allowing yourself to adjust so that you can start to move forwards.
6: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see Further information at the end of this sheet for details).

For ease of reference, we have split the organisations into two sections:

- support for bereaved adults
- support for bereaved children and young people

Support for bereaved adults

Bereavement Advice Centre
Advice on the legal and practical steps to take after someone’s death, including an A5 booklet called What to do when someone dies, A practical guide.
Address: Simplify, Heron House, Timothy’s Bridge Road, Stratford upon Avon CV37 9BX
Freephone: 0800 634 9494
Website: www.bereavementadvice.org

Cruse Bereavement Care
Free bereavement advice and support, including information regarding funeral customs for various cultures.
Address: Cruse Bereavement Care, PO Box 800, Richmond, Surrey, TW9 1RG
Helpline: 0808 808 1677 (Helpline)
Email: helpline@cruse.org.uk or: info@cruse.org.uk
Website: www.cruse.org.uk

Down to Earth
Offer free, practical guidance on finding the most affordable and appropriate funeral. They can also help you to access government support and charitable funds.
Telephone: 020 8983 5055
Email: downtoearth@qsa.org.uk
Website: www.quakersocialaction.org.uk/Pages/Category/down-to-earth

GOV.UK
Online government information about benefits and support.
Email: different contacts are given on the website for various subjects
Website: www.gov.uk
**MND Scotland**
Care, information and research for people affected by MND in Scotland.
Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

**Natural Death Centre**
Support, advice and guidance on planning a funeral.
Address: In the Hill House, Watley Lane, Twyford, Winchester SO21 1QX
Telephone: 01962 712 690
Email: rosie@naturaldeath.org.uk
Website: [www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

**NI Direct**
Government information about health and social care in Northern Ireland.
Email: through the website contact page
Website: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

**Support for bereaved children and young people**

**Child Bereavement UK**
Bereavement support for children and young people facing bereavement.
Address: Clare Charity Centre, Wycombe Road, Saunderton, Buckinghamshire HP14 4PF
Telephone: 01494 568 900
Email: support@childbereavementuk.org
Website: [www.childbereavementuk.org](http://www.childbereavementuk.org)

**ChildLine**
24-hour support for children and young people with any issues they may be facing.
Address: ChildLine, via NSPCC, Weston House, 42 Curtain Road, London EC2A 3NH
Telephone: 0800 1111
Email: through website and confidential login
Website: [www.childline.org.uk](http://www.childline.org.uk)

**Childhood Bereavement Network**
Guidance, information and directions to local and national services for support.
Address: 8 Wakley Street, London EC1V 7QE
Telephone: 020 7843 6309
Email: cbn@ncb.org.uk
Website: [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
Hope Again
Cruse Bereavement Care’s website for young people living after loss.
Address: Hope Again, C/o Cruse Bereavement Care, PO Box 800, Richmond, Surrey TW9 2RG
Helpline: 0808 808 1677
Email: helpline@cruse.org.uk
or children and young people can email: hopeagain@cruse.org.uk
Website: http://hopeagain.org.uk

Winston’s Wish
Bereavement support for children and young people, with a section for parents.
Address: 17 Royal Crescent, Cheltenham, Gloucestershire GL50 3DA
Telephone: 0808 802 0021
Email: info@winstonswish.org.uk
Website: www.winstonswish.org.uk

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References

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

Or write to:
Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Further information

You may find some of our other publications helpful:
Information sheet 9B – How do I support someone if the way they think is affected?
Caring and MND: support for you – a comprehensive pack for carers, including details about respite, emergency care and bereavement

Caring and MND: quick guide – the summary version of the full pack for carers

End of Life: a guide for people with motor neurone disease – includes details about end of life decision making and practical suggestions about what needs to be done when someone dies.

We also provide the following publications to help children and young people find out about motor neurone disease and find ways to cope with the challenges:

Information sheet 4A – Communicating about MND to children and young people

When someone close has MND: a workbook for children aged four to ten - an interactive booklet to help children understand about the disease and develop ways to cope, with guidance from a trusted adult

So what is MND anyway? A publication informing young people about MND from the point of someone’s diagnosis and throughout their journey. We also have a web page for young carers, which gives details about these publications, our services and ChildLine at: www.mndassociation.org/youngcarers

If young people would like to talk about MND with our helpline, MND Connect, they can contact the team in confidence:

Telephone: 0808 802 6262
Email: youngconnect@mndassociation.org

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
MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum
Website: www.mndassociation.org
Online forum: http://forum.mndassociation.org or through the website
MND Association Benefits Advice Service
Our Benefits Advice Service provides advice by phone and email for people living with or affected by MND in England, Wales and Northern Ireland. This service is provided in partnership with Citizens Advice Cardiff and the Vale and Advice NI, by qualified advisers who can help identify benefits you may be entitled to and advise on how to claim. This service is confidential, impartial and free.

England and Wales
Telephone: 0808 801 0620
Email: through the benefits advice page on our website, at: www.mndassociation.org/benefitsadvice

Northern Ireland
Telephone: 0808 802 0020
Email: through the benefits advice page on our website, at: www.mndassociation.org/benefitsadvice

You can also start a live web chat with an adviser through our website if you live in England or Wales. See: www.mndassociation.org/benefitsadvice
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.

If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25

Or request a paper version by email: infofeedback@mndassociation.org

Or write to:
Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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