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## Hospice and Palliative Care


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### Information for people with or affected by motor neurone disease

With a life-shortening illness, hospice and palliative care can help you maintain the best possible quality of life. For maximum benefit with MND, this type of care is recommended from the point of diagnosis onwards. Hospice and palliative care can provide a wide range of help including symptom management, practical advice and emotional support.

While focusing on quality of life, this information sheet also includes information about planning ahead for future care. It includes the following sections:

- 1: **Is there any difference between hospice and palliative care?**
  - 2: **How can hospice and palliative care help me?**
  - 3: **Who provides hospice and palliative care?**
  - 4: **How do I access hospice or palliative care?**
  - 5: **How can this type of care help me plan ahead?**
  - 6: **How do I find out more?**
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 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.



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

## 1: Is there any difference between hospice and palliative care?

Hospice and palliative care are very similar, with the same aims. Hospice care is another way of delivering palliative care services, with the hospice team based in a dedicated building.

A hospice may have some NHS funding, but usually relies on charitable donations. Volunteers often assist at hospices, but clinical care is always provided by specialist palliative care professionals.

Palliative care outside of hospices is simply that given by professionals from wider types of clinic or practice.



*“It’s nice when I’m treated as a whole person and not just an illness.”*

### Where is this care provided?

Hospice or palliative care may be offered in hospitals, hospices, clinics, community venues, nursing homes or in your own home.

There may be waiting lists to access palliative or hospice care. Referrals are usually prioritised on the needs of those waiting to access them.

Services may also differ based on your location and how high demand is for a particular service. To find out what services are available in your area, contact your health and social care team or MND clinic.



*“We should have been told what a hospice is, that it’s not just a place where you go to die. I wish someone had said this to us.”*

### Why is this care important?

Many people think that hospice or palliative care is only provided in the end stages of life. However, where available, this type of care can be provided at any stage of a life-shortening illness.

The earlier you link to these services, the more you can be supported with symptoms, practical help, and psychological, emotional and spiritual support.

This may help you avoid or reduce time spent in hospital for urgent care.

## 2: How can hospice and palliative care help me?

Hospice and palliative care teams help you, but also offer support for your immediate family and carers. They work to improve your wellbeing as a person, rather than just treating your symptoms.



*“Things have improved greatly since my local hospice has become involved... they have stepped in and fought my corner for me and pushed for situations to be resolved. I didn’t realise that their remit was as wide as it is, and they have really lessened our burden.”*

The range of support they can provide may include:

- short-stay care for symptom management
- outreach support in your own home, including community nurse specialists
- physiotherapy, occupational therapy and equipment to maximise your independence
- spiritual and religious support to help you explore and express your personal beliefs
- complementary therapies
- palliative day services, including daily activities
- other treatments or therapies to improve quality of life
- social opportunities, such as support groups and drop-in sessions as part of day services
- practical and financial advice
- family care
- counselling, psychological and emotional support, including bereavement support
- outpatients clinics to see a specialist doctor, and specialist clinics to manage symptoms such as breathlessness
- end of life care.



For related information, see our resources:

- 6A – Physiotherapy,
- 6B – Complementary therapies
- Emotional and psychological support.

### What services are included?

Hospice and palliative care offer a range of services, but these can vary. They usually include:

**Day services:** Some hospices provide day services, where palliative care professionals may be available to assess your needs, control symptoms and provide advice and guidance, if you have any questions or concerns.

Day services may also enable you and your carer to:

- have a short break
- enjoy social activities
- meet others living with life-shortening illnesses, who are likely to know what you are going through and who may be able to offer support
- access complementary and creative therapies, where services are available.

**Support groups:** Hospices and other palliative care services may organise regular support groups. These help you to meet others in similar circumstances, who will understand the challenges you face. You can join a support group at any time.

**Outpatient services:** You usually receive palliative care as an outpatient, which means you are not admitted to stay overnight. Outpatient care is often provided at a clinic, where long-term conditions can be discussed with several health and social care professionals. This may include a consultant, respiratory professional, dietitian, physiotherapist, occupational therapist or speech and language therapist.

**Inpatient services:** You may be admitted to a hospice or hospital for overnight stays if you need treatment or symptom monitoring during palliative care.

**End of life care:** You can be admitted to a hospice or hospital for end-of-life care, if that is your choice. In urgent situations, this may be necessary to ensure you receive the clinical care that is needed.

## How can hospice and palliative care services help my family and carer?

Hospice and palliative care may offer your family and carer:

- psychological and emotional support
- social opportunities
- counselling
- family care
- complementary therapies
- holistic therapies or treatments for mental and social needs as well as symptoms.



*“Before the hospice I felt like I was in a cage.”*

If there are young people in the family affected by MND, there may be hospice staff or palliative care professionals who can provide counselling and emotional support to help them work through any worries.



For resources to help children and young people, see our web hub at [www.mndassociation.org/cyp](http://www.mndassociation.org/cyp)

## Respite care

Some hospices may provide respite care, which is short-term care that allows carers to take a break, or regular breaks. This may provide them with time for shopping, appointments, or to see family and friends.



*“It felt horrible, handing over to the hospice, but it soon became clear he was in the best place possible. The staff were incredible and he was treated like a human being.”*

Adult social care services can also help you arrange respite care and other care support. This requires a needs assessment if you have MND, or a carer’s assessment if you are a carer. Contact your local authority in England, Wales and Scotland, or your local health and social care trust in Northern Ireland to ask for an assessment.

There may be a charge for respite care and care services, but you may receive some help towards these costs, depending on the results of your assessments. However, respite care is sometimes free if provided by a hospice organisation.

## 3: Who provides hospice and palliative care?

Most health and social care professionals have some training in general palliative care. This includes:

- GPs
- district and community nurses
- clinical nurse specialists
- psychologists
- dietitians
- speech and language therapists (SLT)
- social workers
- occupational therapists (OT)
- physiotherapists
- health care assistants.

Specialist palliative care professionals (whether in a hospice or specialist palliative team) have more intensive training and expertise in the management of care for people with life-shortening conditions. These specialists might include:

- consultants in palliative care
- clinical nurse specialists
- community palliative care nurses
- hospice nursing, medical and enablement teams, for example physiotherapists and occupational therapists.



*“Put simply, the palliative care team didn’t pick me up when I stumbled, they caught me before I fell and held me until I got my strength and fight back.”*

Palliative care may also be provided at MND care centres or networks, or local neurological services. The health and social care professionals at these clinics will ideally work together with your specialist palliative care team, in order to provide care that treats you as a whole person.



For more information on MND care centres and networks, see our *Types of care* booklet.

## 4: How do I access hospice and palliative care?

In most cases you can contact your local hospice to ask about available services, without referral.

If you have been diagnosed with MND, ask for referral to palliative care as soon as possible. The earlier you get access, the more benefit you are likely to receive. Your specialist palliative team can help build knowledge about you, that could reduce time spent in hospital if you need urgent treatment.

Having an early referral to a hospice may also help if there are waiting lists to access this type of care in your area.

If you have been referred to a hospice, or for palliative care services, you may have to travel to get to where the service is being provided. However, if you struggle to get out and about, palliative care can be provided at home by community palliative nurses, where these services are available.

### Do I have to pay for this type of care?

Hospice and palliative care services are usually free. They may be NHS funded or funded by a charity or hospice. However, some services may charge, for example if you try a complementary therapy and wish to explore extra options.

## What if I can't access a hospice or palliative care team?

If you are on a waiting list or haven't yet been referred to a hospice or palliative care team, ask your GP or health and social care team for guidance. The NICE guideline on MND may help you open this conversation.

The NICE guideline on MND gives recommendations to health and social care professionals about appropriate care. You can use this guideline to check you are getting suitable treatment and care from your health and social care team.

The guideline recommends that people with MND should have access to a multidisciplinary team, including a professional with expertise in palliative care.



For more information on the NICE guideline on MND, see:  
*Information sheet 1A – NICE guideline on motor neurone disease.*



See our pocket booklet, *What you should expect from your care*, to explore main points from the NICE guideline and help open conversations with your professionals.

If your care does not improve following this discussion, or you are on a waiting list longer than you were told you should be, you may wish to make a formal complaint. Find out how to check if your treatment and care are appropriate at:  
[www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)

## 5: How can hospice and palliative care help me plan ahead?

**This section includes information  
about end-of-life guidance**

End of life care is an extension of specialist palliative care, given when someone appears to be in their last year of life. It focuses on your needs, preferences and wishes, and how to help you die with dignity.

This includes help with planning for future care and end of life decision making.

Building an early relationship with palliative or hospice care teams can enable them, as well as your family, to be aware of your end of life wishes and preferences.



*"I'd go into the hospice and see him, then I'd do the tea trolley and help take it round to all the patients. It was a good experience. Being at the hospice helped me feel more accepting of death and how this could be managed"*

They can also provide support for those close to you, including identifying their needs, and providing bereavement support and counselling.



*“The hospice appointed a ‘friend’ to us, whom my wife talks to a lot. It is really helpful for us and we keep in close contact...when you go there you feel like a friend not a patient.”*

Hospice and palliative care professionals can help you plan ahead by:

- advising on the options available to you
- discussing the advantages and disadvantages of each option
- advising on how to write your wishes correctly, so that your guidance can be used effectively in your care
- directing you to individuals who can provide religious or spiritual end of life support
- helping to facilitate difficult conversations in order to determine your wishes and preferences for end of life
- providing guidance on planning for urgent situations, including ‘just in case’ medications
- supporting with advance planning and financial guidance at the end of life.

## Why should I plan ahead?

End of life decisions usually come from open conversations with family and professionals, which may feel difficult to have. However, discussion and planning ahead can make it easier to arrange things as you wish in the future.

Having these conversations early can also help reduce concerns.



*“Once you’ve done it, you can put it away in a cupboard. You can relax...and you feel better for doing it.”*

Writing your wishes in advance helps you guide others in how you want your future care to be provided. This can give you a sense of control. It also helps reassure everyone involved in your care that they have the knowledge to act on your behalf.

This may help prevent worry, if family or friends do need to make decisions for you.



For comprehensive information on planning ahead for future care, see our guide: *End of Life: a guide for people living with motor neurone disease*



Having early conversations about end of life can be beneficial, as MND can affect:

- speech and communication, making conversations more tiring and difficult over time
- thinking and behaviour, making planning and decision-making more difficult as the disease progresses (this does not affect everyone with MND and is usually mild, but can become more severe for some).



For more information on speech and communication see:

- *Information sheet: 7C - Speech and Communication support*
- *Changes to thinking and behaviour* booklet.

## How can I plan ahead?

As soon as you feel ready, ask your health and social care team about options for future care and planning. You don't have to make immediate decisions, but being informed can help you think about your needs, wishes and best timing for introduction or withdrawal of any treatments.

This will help you make decisions about possible future treatments and the timing of their introduction.

Hospice and palliative care professionals, or your wider health and social care team, can help you with decision making at any point.

There are various ways to guide people in your future care:

**Advance Care Plan** - this records your preferences for the way you want care provided in the future. It is not legally binding but helps guide choices on your behalf. It will only be used if you become unable to make decisions or communicate for yourself.

**Advance Decision to Refuse Treatment (ADRT)** – this also provides guidance if you become unable to make decisions or communicate, but covers decisions to refuse or withdraw specific treatments in advance. If completed correctly, this is a legally binding document.

**DNACPR** – this means Do Not Attempt Cardiopulmonary Resuscitation. You can use this to prevent any medical attempt to restart your heart and breathing, should they stop.

You can be clear about the circumstances in which this would or would not apply (for example, you may want resuscitation if involved in an accident). You can still expect the best possible care if you have a DNACPR.

**Power of attorney** - this grants someone else legal authority to make decisions on your behalf. England and Wales use Lasting Power of Attorney, that can cover either care needs, financial decisions or both. Northern Ireland uses Enduring Power of Attorney, which can only apply to financial affairs. Scotland uses Continuing Power of Attorney which only applies to financial and property affairs.

**Understanding my needs** – our form helps you record your MND care needs. This can guide medical and care staff if you need to be admitted to a hospital or hospice. It can also guide care workers in your home or a nursing home.

We provide more detailed help and who can support you with the creation and use of these documents.



See our resources:

- Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*.
- *End of life – a guide for people with motor neurone disease* and lots of information on our website: [www.mndassociation.org/planningahead](http://www.mndassociation.org/planningahead)
- *MND Alert Card*
- *MND Alert Wristband*.

## 6: How do I find out more?

### Useful organisations

We do not endorse organisations, but have included this list to help you search for further information.

Details are correct at the time of print, but contact our MND Connect helpline if you need help to find a service (see *Further information* at the end of this sheet for helpline details).

#### Dying Matters

Help to start conversations about dying, death and bereavement.

Telephone: 08000 21 44 66

Email: through the website contact page

Website: [www.hospiceuk.org/our-campaigns/dying-matters](http://www.hospiceuk.org/our-campaigns/dying-matters)

#### Hospice UK

Guidance and a search facility for hospices in the UK.

Telephone: 020 7520 8200

Email: through the website contact page

Website: [www.hospiceuk.org](http://www.hospiceuk.org)

### **Macmillan Cancer Support**

Help and guidance on cancer, but some end-of-life support for other conditions.

Telephone: 0808 808 0000

Email: through the website contact page

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

### **Marie Curie**

Charity providing palliative and end of life care support.

Telephone: 0800 090 2309

Website: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

### **Northern Ireland Hospice**

Charity offering respite, symptom management and end of life care across Northern Ireland, including Hospice at Home services.

Telephone: 028 9078 1836 (head office)

Website: [www.nihospice.org](http://www.nihospice.org)

### **Sue Ryder**

Charity with guidance on hospice care for life-shortening conditions.

Telephone: 0808 164 4572

Email: through the website contact page

Website: [www.sueryder.org](http://www.sueryder.org)

## **References**

References used to support this document are available on request from:

Email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to: Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd, Moulton Park, Northampton NN3 6BJ

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## Further information

We provide a range of information sheets, including:

1A – *NICE guideline on motor neurone disease*

6A – *Physiotherapy*

6B – *Complementary therapies*

14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

We also provide the following guides and booklets:

*Living with motor neurone disease* – comprehensive guide to MND, which provides an overview of the disease and how to manage its impact.

*What you should expect from your care* – pocket booklet to support conversations with professionals about your Care, based on the NICE guideline.

*Types of care* – overview of the range of care available including primary care, specialists, as well as MND care centres and networks.

*Emotional and psychological support* – identifying difficult emotions that may happen for people with a diagnosis of MND and their carers.

*Changes to thinking and behaviour with MND* – guide to identifying changes that may happen and the support available.

*Telling people about MND* – how to open conversations about your diagnosis with family, children, friends, colleagues and health and social care professionals.

*Caring and MND: support for you* – comprehensive information for unpaid or family carers, who support someone living with MND.

*Caring and MND: quick guide* – the summary version of our information for carers.

*So what is MND, anyway?* – a comprehensive guide about MND for young people and young carers.

*When someone close has MND: Workbook for children aged 4-10* – interactive workbook to help children communicate about MND with a trusted adult.

*End of Life: a guide for people living with motor neurone disease* - provides guidance on how to plan ahead and communicate your choices to family and professionals.

You may find our alerts useful:

*MND Alert Wristband* – lets emergency and hospital staff know you have MND. Carries a clear caution that oxygen therapy may put someone with MND at risk.

*MND Alert card* – To carry in a purse, wallet or pocket to let emergency and hospital staff know you have MND.

*Understanding my needs* – allows you to record your wishes and preferences for care, to assist health and social care professionals to understand your needs.

You can download most of our publications from our website at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or order in print from the MND Connect helpline, who can provide further information and support.

You can also search for content by need by using the care information finder on our website: **[www.mndassociation.org/careinfinder](http://www.mndassociation.org/careinfinder)**

MND Connect can also help locate external services and providers as well as introducing you to our services.

#### **MND Connect**

Telephone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park, Northampton NN3 6BJ

#### **MND Association website and online forum**

Website: **[www.mndassociation.org](http://www.mndassociation.org)**

Online forum: **<https://forum.mndassociation.org>** or through the website

## **We welcome your views**

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:  
**[www.smartsurvey.co.uk/s/infosheets\\_1-25](http://www.smartsurvey.co.uk/s/infosheets_1-25)**

You can request a paper version of the form or provide direct feedback by email:  
[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback, MND Association, Francis Crick House,  
6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ

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