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Hospice and palliative care

Information for people with or affected by Motor Neurone Disease (MND)

Hospice and palliative care can help you maintain the best possible quality of life during a life-shortening illness. Offering a wide range of help, it can provide symptom management, and practical and emotional support. For maximum benefit, this type of care is recommended with MND from the point of diagnosis. This information sheet explores how this support works. The content includes:

- 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 and palliative care?**
- 5. How can this type of care help me plan ahead?**
- 6. How do I find out more?**



This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5
How do I find out more?

**This information sheet includes details about planning for future care.
Read when you feel ready to do so.**

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.

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.



"It's nice when I'm treated as a whole person and not just an illness."

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 demand for a particular service. Find out about available services in your area by contacting your health and social care team or MND clinic.

Why is this care important?



“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.”

Many people think that hospice or palliative care is only provided if you’re in the end stages of life. However, where available, this type of care can be provided throughout 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 work to improve your wellbeing as a person, rather than just treating your symptoms. They also offer support for your immediate family and carers. Their support 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 as long as possible
- 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 their day services
- practical and financial advice
- family care
- counselling, psychological and emotional support, including bereavement support
- outpatient clinics to see specialist professionals, and specialist clinics to manage symptoms such as breathlessness
- end of life care.



“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.”



See our resources:

- information sheet **6A Physiotherapy**
- information sheet **6B Complementary therapies**
- our booklet: **Emotional and psychological support.**

What services are included?

Hospice and palliative care offer a range of services, but these can vary.

Day services: Some hospices provide day services, where your needs can be assessed by palliative care professionals for symptom control, advice and guidance. Day services may also help you and your carer to:

- have a short break
- enjoy social activities
- meet others living with life-shortening illnesses for sharing and 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:

- guidance on your needs
- psychological and emotional support, through counselling
- social opportunities
- family care
- complementary or holistic therapies, or treatments for their own mental and social needs.



“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. This can help them work through any worries.



For resources to help children and young people, see our web hub at:
mndassociation.org/cyp

Respite care

Some hospices may provide respite care, which provides you with short-term care to allow your carer 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 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 to ask for an assessment, or your local health and social care trust in Northern Ireland.

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, including:

- 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 (in hospice or palliative care teams) have more intensive training 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.



See our booklet: **Types of care.**

4. How do I access hospice and palliative care?

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

When referred to a hospice or to palliative care services, you may need to travel to where the service is provided. However, if needed, palliative care can be provided at home by community palliative nurses, where this support is 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 free complementary therapy but then 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 about the NICE guideline on MND, see information sheet: **1A - NICE guideline on motor neurone disease** and our pocket booklet: **What you should expect from your care** to help at appointments.

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:
mndassociation.org/mycare

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

This section includes guidance about planning future care at end of life. Read when you feel ready to do so.

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



“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.”

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,
- supporting with advance planning and financial guidance at the end of life.



“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.”

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 makes it easier to arrange things, so they happen in the way you prefer. Having these conversations early can also help reduce concerns.

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 and 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.

Having early conversations about end of life can be helpful 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 be more severe for some).



See information sheet: **7C Speech and communication support** and our booklet: **Changes to thinking and behaviour with MND**.

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 preferences. It can also help you explore best timing for introduction or withdrawal of any treatments.



"Once you've done it, you can put it away in a cupboard. You can relax... and you feel better for doing it."



See our guide: **End of life care: for people with motor neurone disease** for more about decision-making.

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 enables you to give guidance in advance, on decisions to refuse or withdraw specific treatments. If completed correctly, this is a legally binding document, but will only be used if you become unable to make or communicate decisions for yourself.

DNACPR

This means Do Not Attempt Cardiopulmonary Resuscitation. Use this if you want 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 only applies 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.



See our web page: mndassociation.org/planningahead for more about decision-making and other resources, including our MND alert card and MND alert wristband.

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Dying Matters

Help to start conversations about dying, death and bereavement.

Tel: 020 7520 8200

Email: through the website contact page

Website: hospiceuk.org/our-campaigns/dying-matters

Government information

Online government information about benefits and support in

Website: gov.uk (England and Wales)

nidirect.gov.uk (Northern Ireland)

gov.scot (Scotland)

Hospice UK

Guidance and a search facility for hospices in the UK.

Tel: 020 7520 8200

Email: through the website contact page

Website: hospiceuk.org

Macmillan Cancer Support

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

Tel: 0808 800 0000

Email: through the website contact page

Website: macmillan.org.uk

Marie Curie

Charity providing palliative and end of life care support.

Tel: 0800 090 2309

Website: mariecurie.org.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903

Email: info@mndscotland.org.uk

Website: mndscotland.org.uk

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website **nhs.uk**

Telephone 111 (for urgent medical advice in England, available 24/7)

Website **111.nhs.uk** (For England)

Telephone 111 (for urgent medical advice in Wales, available 24/7)

Website **111.wales.nhs.uk** (For Wales)

Telephone Find individual trusts in Northern Ireland on website contact page

Website **hscni.net** (For Northern Ireland)

Telephone 111 (for urgent medical advice, available 24/7)

Website **nhs24.scot** (For Scotland)

Northern Ireland Hospice

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

Tel: 028 9078 1836 (head office)

Email: through the website contact page

Website: **nihospice.org**

Sue Ryder

Charity with guidance on hospice care for life-shortening conditions

Tel: 0808 164 4572

Email: through the website contact page.

Website: **sueryder.org**

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Carol Bradley Deciding Right Facilitator, St Mary's Hospice, Lancaster.

Dr Claire Stockdale Consultant in Palliative Medicine, Seven Hospice, Shrewsbury.

References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A NICE guideline on motor neurone disease
- 6A Physiotherapy
- 6B Complementary therapies
- 14A Advance Decision to Refuse Treatment (ADRT) and advance care planning

Booklets

Emotional and psychological support
Types of care
Changes to thinking and behaviour with MND
Telling people about MND
What you should expect from your care
Caring and MND - quick guide

Large guides

Living with MND
Caring and MND - support for you
So what is MND, anyway?
When someone close has MND: Workbook for children aged 4-10
End of Life care: a guide for people with motor neurone disease

Other resources and alerts

MND Alert Wristband
MND Alert card
Understanding my needs

Search for information by need at: mndassociation.org/careinfofinder
Find information for professionals at: mndassociation.org/professionals
Download our information at: mndassociation.org/publications
Find information in other languages at: mndassociation.org/languages
Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: **mndassociation.org/our-services**

Local and regional support

Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**

Online forum: **forum.mndassociation.org**

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at: **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**

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at: **infofeedback@mndassociation.org**

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