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Hospice and palliative care

Information for people with or affected by motor neurone disease

The aim of hospice and palliative care is to help you have the best possible quality of life with a life-shortening illness. 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.

This information sheet explains how hospice and palliative care can help you with 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?**

Please be aware that while this sheet focuses on quality of life, it also includes information about planning ahead for future care. Read when you feel ready to do so.

 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?

Palliative care aims to improve the quality of life of people with a life-shortening illness and their families. This is achieved by providing symptom management and psychological, social and spiritual support. This care may be provided in a variety of settings, including hospitals and in the community in people's homes.



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

It can be provided on a general or more specialised basis, depending on individual needs. Different professionals provide these different levels of palliative care, see section 3: *Who provides hospice and palliative care?* for more information.

Many people think that palliative care is only provided in the end stages of life. However, where available, palliative care can be provided at any stage of a life-shortening illness. The earlier you link in to these services, the more they can support you.

Hospice care is specialist palliative care that is linked to a specific hospice organisation. However, the care may be delivered in different settings, not just at the hospice itself.



"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."

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. Hospice care is simply another way of delivering palliative care services.

There may be waiting lists to access palliative or hospice care, as referrals are usually prioritised on the needs of the people wanting 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.

2: How can hospice and palliative care help me?

Hospice and palliative care teams are there to help you, your carers and those important to you. Palliative and hospice care teams work to improve your wellbeing by treating you as a whole person, rather than just any symptoms you may have.



"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, eg 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:
Information sheets 6A – Physiotherapy, 6B – Complementary therapies
and 9C – Managing emotions.



“Professionals often say that people with MND and their families do not want to access specialist palliative care shortly after diagnosis – it is too soon. However, once people with MND have accessed specialist palliative care services they say they wished they had accessed services earlier”

All Party Parliamentary Group (APPG) for the MND Inquiry
into access to Specialist Palliative Care for people with MND, 2011.

What services can palliative care offer?

Hospice and palliative care may offer a range of services, as listed below.

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 and advice
- 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 have an understanding of the challenges you face. You may not want this kind of support at first, but if you change your mind, you can join a support group at any time.

Outpatient services: In most cases, you will receive palliative care as an outpatient, which means you do not need to stay overnight to receive care. 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 or occupational therapist.

Inpatient services: You may be admitted for a short while at a hospice or hospital if you need treatment or symptom monitoring as part of your palliative care. This could include overnight stays.

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

Hospice and palliative care teams also provide support for your family and carer. This includes many of the types of support discussed above, including:

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



"Before the hospice I felt like I was in a cage."

Hospice and palliative care can enable your family and to take a break from the caring role, and save energy to do the things you all enjoy. 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 information aimed at young people affected by MND, including details about hospice and palliative care, see our young person's guide: *So what is MND, anyway?*



We also have a workbook aimed at a younger audience, see: *When someone close has MND: a workbook for children aged 4-10*

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 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 usually 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.

However, 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 illnesses. These specialists might include:

- consultants in palliative care
- clinical nurse specialists
- community palliative care nurses
- hospice nursing, medical and enablement teams, eg 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 care centres, see:
Information sheet 3A – *MND care centres and networks*

4: How do I access hospice and palliative care?

Most hospice and palliative care services require referrals from a GP, or another member of your health and social care team, to access them. However, some hospices allow self-referrals.

If you have been diagnosed with MND, ask to be considered for early referral to a palliative care team as soon as possible. The earlier you build a relationship with palliative care professionals, the more benefit you are likely to receive. The knowledge a specialist palliative care team or hospice can build about you can also help to reduce any time spent in hospital if urgent or emergency treatment is required.

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 a wider selection than is offered by the palliative care service.

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

If you are on a waiting list to access a hospice or palliative care team, or have been unable to get a referral, have a discussion about this with your GP or another member of your health and social care team. 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 how to provide 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*

 We also provide a small pocket booklet, *What you should expect from your care*, which features the main points from the NICE guideline and can be used to help open conversations about your care with 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. We provide more information on how to check if your treatment and care are appropriate at:
www.mndassociation.org/mycare

The following section includes information about the end of life. You may not want to read any more at this stage. You can refer to this section when you feel ready.

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

End of life care is part of the palliative care approach, but is provided for people who are thought to be in the last year of life. It tends to focus on the needs, preferences and wishes of the person approaching death and how to help them 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 know what your end of life wishes and preferences are.



"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 difficult 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 down your wishes in advance also means you can explain how you would like your future care to be provided. This can be beneficial if those involved in your care need to act on your behalf.

This may give you a sense of control, knowing that those involved in your care know exactly how you would like it to be provided. Knowing exactly what your wishes and preferences are for your future care may also give your loved ones a sense of comfort and reassurance.

This may prevent any doubts or disagreements about what would be best for your future or end of life care, if other people such as family members or trusted friends need to make these 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 reasoning for some people, making planning and decision-making more difficult as the disease progresses (if this happens it is usually mild, but can be more severe for some people).

How can I plan ahead?

As soon as you feel ready, ask your health and social care team about your options for future care and planning. This does not mean you have to make immediate decisions, but being informed can help you discuss your needs, preferences and wishes.

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

Hospice and palliative care professionals, as well as your wider health and social care team, can help you with decision making.

You can write down instructions about the medical and social care you would wish to receive or not receive in certain situations.

Creating an Advance Care Plan enables you to set out your preferences for your future care. It is not legally binding, but helps guide choices on your behalf if you become unable to make decisions or communicate for yourself.

An Advance Decision to Refuse Treatment (ADRT) enables you to write down decisions to refuse or withdraw specific treatments in advance. If completed correctly, this is a legally binding document.



For more on planning ahead for future care, see:
Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*
and *End of life: a guide for people with motor neurone disease*.

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 or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Conversations for Life

Help for families, professionals and communities to start discussions about end of life care.

Address: 2 The Mill Yard, Staveley,
Cumbria LA8 9LR UK
Telephone: 01539 821420
Email: info@conversationsforlife.co.uk
Website: www.conversationsforlife.co.uk

Dying Matters

A membership organisation offering a wide range of resources to help people start conversations more easily about dying, death and bereavement.

Telephone: 08000 21 44 66
Website: www.dyingmatters.org

Find me Help

Online service to help you find local services that can assist with end of life needs. This is hosted on the Dying Matters website.

Website: www.help.dyingmatters.org

Hospice UK

Charity which supports hospice care providers to deliver high quality care and support for people with life-shortening illnesses and their families.

Address: Hospice House, 33-34 Britannia St,
London WC1X 9JG

Telephone: 020 7520 8200

Website: **www.hospiceuk.org**

Macmillan Cancer Support

Macmillan mainly focuses on supporting people affected by cancer. However, they do provide some support for non-cancer patients. Ask your health and social care team for advice about Macmillan nurses and services in your area.

Address: Macmillan Cancer Support, 89 Albert Embankment,
London, SE1 7UQ

Telephone: 0808 808 0000

Email: through the website contact page

Website: **www.macmillan.org.uk**

Marie Curie

Charity providing palliative and end of life care and support for people with terminal illnesses.

Telephone: 0800 090 2309

Website: **www.mariecurie.org.uk**

The National Council for Palliative Care

The umbrella charity for all charities involved in palliative, hospice and end of life care in England, Wales and Northern Ireland which works to improve end of life care for everyone.

Address: Hospice House, 33-34 Britannia St,
London WC1X 9JG

Telephone: 020 7697 1520

Website: **www.ncpc.org.uk**

Northern Ireland Hospice

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

Address: 18 O'Neill Road, Newtownabbey BT36 6WB (head office)

Telephone: 028 9078 1836 (head office)

Website: **www.nihospice.org**

Sue Ryder

A charity which provides hospice and neurological care for people with life-shortening illnesses.

Address: First floor, 16 Upper Woburn Place
London WC1H 0AF

Telephone: 0845 050 1953

Email: info@sueryder.org

Website: www.sueryder.org

References

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

Email: infofeedback@mndassociation.org

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

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Further information

You may find these information sheets from the MND Association helpful:

1A – *NICE guideline on motor neurone disease*

3A – *MND care centres and networks*

6A – *Physiotherapy*

6B – *Complementary therapies*

9C – *Managing emotions*

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

We also provide the following resources:

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

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

We also provide the following tools that you may find 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.

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

MND Just in Case Kit – enables a GP to prescribe medications for a person with MND to keep close at hand, in case of sudden changes with breathlessness, feelings of panic or choking.

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

www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.



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

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.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, MND Association, PO Box 246 Northampton NN1 2PR



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