

3A

MND care centres and networks


Information for people with or affected by motor neurone disease, or Kennedy's disease


The MND Association part-funds a national partnership programme of MND care centres and networks across England, Wales and Northern Ireland.

This information sheet explains how care centres and networks assist people living with motor neurone disease (MND) or Kennedy's disease. This sheet provides an overview, but there may be differences in the way each care centre or network works. To find out more, contact the relevant co-ordinator (see section 4: : *How do I get an appointment?*)

The content includes the following sections:

- 1: What are MND care centres and networks?**
- 2: What services do they provide?**
- 3: Who might I see at an appointment?**
- 4: How do I get an appointment?**
- 5: 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.

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

1: What are MND care centres and networks?

MND care centres and networks are dedicated MND clinics where people come together to improve the standard of care for people living with MND or Kennedy's disease. These clinics pull together a team of different professionals (known as a multidisciplinary team) who work in a co-ordinated way. They monitor and advise on symptoms and provide support and information.

MND care centres are not purpose built buildings. Appointments usually take place in a hospital or hospice. In most cases you need to travel to these appointments. MND Care networks offer an outreach service.

The coronavirus pandemic has prompted a huge advance in remote consultation. You will still need to be seen in person for physical assessments or tests, but more health and social care professionals are using technology for video appointments. Much can be achieved this way and if you find travel difficult, this may be a useful option in some situations. Ask what is available and recommended in advance of an appointment.

The professionals at your MND care centre or network will not replace your existing health and social care team, but work with them. Their main aim is to improve support and co-ordination of services for people living with MND.



"The care centre staff are brilliant. It's a great place to go to solve medical problems and it's good to meet other people with MND as well"

It is important to note that most neurology clinics offer co-ordinated care and services for MND. The MND Association works in partnership with neurology and community services, as well as MND care centres and networks.

Our aim is to improve services and help people with MND or Kennedy's disease receive equal care at the highest standard possible. MND Connect can help direct you to related services. See *Further information* in section 5: *How can I find out more?* for contact details.

How are networks different to care centres?

Although they provide similar services the main difference is that a care centre is usually based in a hospital, whereas a network usually offers an outreach service in a varied location, where a central clinic isn't available. In some cases, this may include home visits.

Some MND care centres and networks have 'research' in their title, but anyone can apply to be involved in research regardless of which care centre or network you go through. See heading: *How can I get involved in research?*

MND care networks cover six areas:

- The Norfolk MND Care and Research Network
- The Northern Ireland MND Care Network
- The North Midlands MND Care and Research Network
- The South Wales MND Care Network

- The South Western Peninsula MND Care Network (Devon and Cornwall)
- The Sussex MND Care and Research Network

For contact details, see section 4: *How do I get an appointment?*

2: What services do they provide?

MND care centres and networks can provide:

- a single point of contact for people with MND, called a care centre or network co-ordinator
- expertise in the management of MND
- strong links with local community services
- strong links with the MND Association
- the sharing of good practice with other colleagues in the community to educate and spread expertise across the region
- access to a multidisciplinary team (see heading: *Who might I see at an appointment?*).

If you attend a care centre hospital clinic, a network clinic, or are reviewed at home, you may be offered:

- regular monitoring by a neurologist with expertise in MND
- blood tests and breathing tests
- assessment and support from a team of specialists working together
- advice and information
- a proactive service which thinks about your future needs and can make referrals as needed
- an opportunity to see more than one therapist when you visit the clinic
- an opportunity to be involved in new research projects
- where possible, guidance for your carer to support their caring role.

How can I get involved in research?

We know how keen some people are to get involved in research. Some studies and trials need the participation of people with MND, and sometimes people without MND.

If you attend a care centre or network, you may hear about upcoming research they will be hosting. However, you do not need to be attending one to take part in research. Ask your neurologist about trials you may be eligible for and they can arrange a referral.

To see a list of research opportunities in the UK see our website: **www.mndassociation.org/take-part-in-research**. You will be able to see what is involved, where the trials are taking place and their contact details.

You can also sign up to our research participation mailing list to receive emails about new research opportunities: **www.mndassociation.org/mnd-research-list**

Or you can contact our research team:

Telephone: **01604 611 880**

Email: **research@mndassociation.org**

How does the MND care centre or network link with my local services?

The MND care centre or network team works closely with colleagues in the community to encourage good communication about how to manage your care.

They will let your GP and other professionals involved in your care know the outcome of your visit. The care centre or network co-ordinator ensures information is passed on to local services and appropriate support is in place at home.

MND Association regional staff and care centre co-ordinators have regular meetings with local community teams. Local therapists are also welcome to visit the MND care centre or network.

3: Who might I see at an appointment?

As with most neurological clinics, a range of professionals come together at MND care centres or networks to support people living with MND. This is called a multidisciplinary team (MDT). When professionals work together in this way, it allows them to share information and co-ordinate your care more effectively.

The size of the team varies, but it will usually include the following:

Neurologist

A doctor who specialises in the brain, spinal cord, nerves and muscles. They are experts on conditions such as MND and usually work with other medical consultants to ensure people with MND receive the best possible medical care. The neurologist is usually the care centre director in charge of the overall management of the service.

Care centre co-ordinator

This person is the main contact for anyone wishing to access the MND care centre or network service. Communication is central to the co-ordinator's role, linking people with the multidisciplinary team, community services and the MND Association.

MND Association visitors (AV)


AVs are volunteers who provide free and confidential personal support to people living with MND, their carers, their family and close friends. In some MND care centres or networks, MND Association visitors are present on clinic days.

Occupational therapists (OTs)

OTs support people to remain as independent as possible through equipment for daily living, adapting the home environment and informing people of different ways to do everyday activities. Some centres or networks may have specialist wheelchair OTs.


Physiotherapists

Physiotherapists offer guidance on managing symptoms such as fatigue, cramps and spasticity in the muscles. They can advise on suitable exercise and positioning to maximise comfort. Physiotherapy cannot reverse damage to muscle groups weakened by MND, but it can help maximise the use of muscles that are not yet affected and increase flexibility by maintaining movement of your joints.

 For more detailed information about physiotherapy, see: Information Sheet 6A – *Physiotherapy*

Psychological support team

You may also be able to access a social work team, a neuro psychologist or a clinical psychologist who will be able to support you and your family.

 For more information about emotional and psychological support, see our booklet: *Emotional and psychological support*.

Speech and language therapist (SLT)


SLTs offer advice, assessment and treatment for people with speech, language and communication difficulties. They also work with people who have problems with eating and swallowing.

Dietitians

Dietitians are experts in nutrition. They work closely with speech and language therapists to help you maintain a healthy weight where swallowing might be difficult. They can advise you on eating and drinking, as well as tube feeding.

Palliative care specialists

Palliative care specialists work to improve the quality of life for people with life-shortening conditions. This can include a wide range of support including symptom control and support for any psychological, social, spiritual, religious or other needs.

 For more information on palliative care, see: Information sheet 3D – *Hospice and palliative care*

Respiratory team

This may include a respiratory consultant and a specialist physio who are experts on breathing issues.



For more information on breathing with MND, see:
Our breathing and ventilation information sheet range, 8A-E

MND Association regional staff have expert knowledge of the management and care of people with MND. They work closely with local service providers to ensure care and support is available at the right time, and they may communicate with a member of the MDT in certain circumstances.

4: How do I get an appointment?

If you want to access an MND care centre or network, you will need to be referred by a GP, neurologist, or other healthcare professional.

How do I make contact?

If you would like to find out more about any individual MND care centre or network, please contact the co-ordinator directly by telephone or email to discuss your situation. They can then explain how you can be referred and discuss what support they can offer. Their details are shown in this section and on our website at:

www.mndassociation.org/carecentres

You can also contact our MND Connect helpline for information about the care centres or networks, or any concerns about their service. See *Further information* in section 5: *How can I find out more?* for contact details.

If you start attending a care centre or network, check with them if there will be any contact between appointments. You may be able to email them with any queries.

Where is my nearest MND care centre or network?

The care centres and networks currently operate in the following locations. Contact the appropriate care centre co-ordinator using the telephone number provided:

Birmingham

Telephone: 07771 624712 or 0121 3715800

Bristol

Telephone: 0117 414 0803

Cambridge

Telephone: 01223 216631 ext 2631

Lancashire and South Cumbria
Telephone: 01772 522545

Leeds
Telephone: 0113 392 6078

Liverpool
Telephone: 0151 529 5070 or 0151 529 5624

London – Barts
Telephone: 020 3594 1883

London – Kings College
Telephone: 020 7848 5172

London – The National
Telephone: 0845 155 5000 or 020 3448 3517

Manchester
Telephone: 0161 206 2920

Middlesbrough
Telephone: 01642 854318

Newcastle
Telephone: 0191 282 3693

Norfolk Network
Telephone: 01603 647221

Northern Ireland Network
Telephone: 02890 632103

North Midlands Network
Telephone: 01782 671404

Nottingham
Telephone: 0115 970 9142

Oxford
Telephone: 01865 737460

Sheffield
Telephone: 0114 222 2266

Southampton
Telephone: 02381 206 544

South Wales Network
Telephone: 02920 313828 or 01792 703705

South West Peninsula Network (Devon and Cornwall)
Telephone: 01752 436 759

Sussex Network
Telephone: 01273 876 541

5: 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).

Health in Wales

Online information on NHS services in Wales.

Website: www.wales.nhs.uk

MND Scotland

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

Address: Unit 8, 76 Firhill Road, Glasgow G20 7BA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

National Institute for Health and Care Excellence

An independent organisation providing national guidelines on preventing, diagnosing and treating ill health, including NG42 on the assessment and management of MND. The guideline includes a section on NIV.

Address: 2nd floor, 2 Redman place, London, E20 1JQ

Telephone: 0300 323 0140

Email: nice@nice.org.uk

Website: www.nice.org.uk

NHS Website

The main online reference for the NHS.

Email: through the website contact page

Website: www.nhs.uk

NHS 111

The NHS online/telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

Website: **111.nhs.uk**

NHS 111 Wales

Health advice and information service for Wales.

Telephone: 0845 4647 or 111 if available in your area.

Website: **https://111.wales.nhs.uk**

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page

Website: **http://online.hscni.net**

NI Direct

Provides government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Website: **www.nidirect.gov.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, Francis Crick House,
6 Summerhouse Rd, Moulton Park, Northampton NN3 6BJ

Further information

We provide information sheets and publications on a range of subjects.

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

MND Association website and online forum

Website: **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

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

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