NHS
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The Sussex Motor Neurone Disease (MND) Care and Research Network

Neurology



Patient information

What is this information about?

This information is about what happens after you have been diagnosed with Motor Neurone Disease (MND); the specialist MND Clinic, who will be involved in your care; details about the Sussex MND Care and Research Network; and details of contacts who can give you further information and advice.

I have been diagnosed with MND. What happens next?

You may have been offered an appointment at the specialist MND clinic. This clinic is also called the Motor Movement Disorder Clinic. Your GP or consultant will need to refer you for this.

This clinic is run by Dr Andrew Barritt. You may also see other consultant neurologists (doctors who specialise in the brain).

Rachel Thomson, the MND Network coordinator may be there, as well as other healthcare professionals and students.

What will happen at the MND clinic?

The focus of this clinic is to:

- confirm your diagnosis
- provide information about MND
- refer you to other services as needed.

We may talk with you about taking part in research studies. You may be able to take part in research if this is right for you.

Usually, this appointment is a one-off. Your ongoing neurology care will continue with your local neurologist.

Where is the Sussex MND Care and Research Network Clinic?

The clinic address is:

Sussex MND Care and Research Network Clinic
University Hospitals Sussex
Level 3, Louisa Martindale building
Royal Sussex County Hospital
Eastern Road, Brighton BN2 5BE

Who else will be involved with my care?

You will be referred to your local MND Specialist Practitioner. They work in the community supporting people with MND. They will be your main point of contact for your MND care. They work for local community NHS Trusts.

The MND practitioner will be in touch with you within a few weeks to arrange to meet you at home. They will arrange input from any other professionals you may need help from (like a physiotherapist). They will see you at home on a regular basis.

MND Specialist Practitioner contact details

Brighton & Hove:

Kirsty Brett

01273 265984

Sc-tr.mndservicesbrightonandhove@nhs.net

Chichester area:

Sandra Mowat

01243 793618

sc-tr.cnrtwest@nhs.net

Eastbourne, Hailsham, Seaford:
Vicky Lester. Press option 2
01323 466565
esht.mndco-ordinators@nhs.net

Mid Sussex, Crawley, Horsham:
Hannah Doubleday
01403 620437
sc-tr.mnd@nhs.net

Hastings & Rother:
Margie Haley
01424 726750
esht.mndco-ordinators@nhs.net

Worthing area:
Fiona Eldridge
01273 242289
sc-tr.mndsouth@nhs.net

High Weald, Lewes & Havens area:
Simon Wilson. Press option 2
01273 336600
esht.mndco-ordinators@nhs.net

There is an MND multi-disciplinary team (MDT) for each area of Sussex. A multi-disciplinary team is a group of professionals from different areas of health and social care who provide care for individual patients. These teams meet regularly to discuss the care of all patients with MND in that area.

Who should I contact for information and advice about my symptoms?

If you have questions about your MND symptoms, please contact your MND specialist practitioner, your neurologist or primary care team.

The Sussex Motor Neurone Disease Care and Research Network cannot provide advice in an emergency.

What is the Sussex Motor Neurone Disease Care and Research Network?

The Sussex Motor Neurone Disease Care and Research Network was set up in 2016 with support from the MND Association.

The aim of the network is to:

- strengthen and improve care and support services for people affected by MND in Sussex
- increase access to MND research for people with MND.

How will we achieve our aims?

We work with local health and social care professionals, hospices and the MND Association to improve care and support for people in Sussex.

We run a specialist MND clinic in the Royal Sussex County Hospital.

We take part in a variety of MND research studies.

How do I contact the MND Care and Research Network?

For questions about MND in general or the MND Network, please contact:

Rachel Thomson, Coordinator (working days Monday to Thursday)

University Hospitals Sussex Level 3 Neuroscience offices, Louisa Martindale Building, Royal Sussex County hospital, Eastern Road, Brighton BN2 5BE.

07768 526114

Rachel.thomson1@nhs.net

Sussex MND Care and Research Network
www.uhsussex.nhs.uk/services/neurology/sussex-motor-neurone-disease-care-and-research-network

Where else can I find information and support about MND?

The **MND Association** **https://www.mndassociation.org/** is a membership organisation for people affected by MND. The Association improves care and support for people with MND, their families and carers.

The MND Connect team offers information and support on all aspects of motor neurone disease (MND), including symptom control, practical management, improving quality of life, clinical research and signposting to other organisations.

MND Connect is available Monday to Friday between 10am to 4pm.

MND Connect

0808 8026262 **mndconnect@mndassociaton.org**

Local branches and support groups

Local contact:

Lisa Burnard, area support coordinator for Sussex
01604 800611

There are three MND Association branches in Sussex. They offer support, social events and fundraising.

East Sussex branch: www.mndaeastsussex.org.uk

West Sussex South: www.mndawestsussexsouth.co.uk

West Sussex North: www.mndwestsussexnorth.com

Today's research is tomorrow's treatments.
That's why UHSx is proud to be a research-active Trust.

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