



East Kent Motor Neurone Disease (MND) Multidisciplinary Team

Support, advice, and help for those affected by MND

Motor Neurone Disease (MND) affects people in many different ways. Every person with the disease will be different. Problems will often affect the person with the disease, and their family and carers.

What is the purpose of the MND Team?

The aim of the team is:

To help people with MND and their families and carers. To co-ordinate care to reduce the disruption to life as much as possible. To achieve this, the professionals involved hold a confidential meeting. At this meeting they share information, ideas, and experiences. This helps them to make sure that you receive the best possible service.

Who are the East Kent Motor Neurone Disease Team?

The East Kent MND Team supports people living with MND. The team includes an MND nurse and various community health professionals, including:

- occupational therapists
- dieticians
- speech and language therapists
- physiotherapists
- communication aids specialists
- MND Association volunteer visitors
- a regional care and development advisor.

The multidisciplinary team meet every 6 to 8 weeks. Together they discuss each patient known to the east Kent team. The team share information at this meeting, so they can provide a seamless service between

teams.

The team liaises with the:

- MND Regional Care Centre
- Research Centre at Kings College Hospital London
- neurologists; and
- other specialist teams.

What team members might I meet at clinics and in my home?

MND clinics are held at the William Harvey Hospital (WHH), Ashford twice a month. At these clinics we will make a careful assessment of your condition. Other specialists may be available to provide help and advice.

- **MND nurses**

The Trust has two MND nurses to support, help, and provide information to those living with MND, their family, and their carers. The nurses can:

- complete referrals to other health and social care professionals for specialist assessment; and
- link-up with community therapists, to achieve a co-ordinated approach to your care.

The MND nurses will review you at regular intervals in clinic, and sometimes in your own home.

They will also contact your GP. This is to make your GP surgery aware of the team's involvement, so they can share in the team approach to your care. The MND nurses are also at the twice monthly clinic held at WHH.

- **Physiotherapists (via the Intermediate Care Team)**

Your physiotherapist will teach you exercises that will:

- help keep your joints moving; and
- help with any pain and stiffness you have.

They will provide advice, equipment, and appliances to help you move around and carry out your daily activities.

The physiotherapists will also help you keep good positions when sitting and standing. This will help with your comfort. It will also reduce any problems linked with muscle weakness and joint stiffness.

The physiotherapists can also advise you if you have any breathing difficulties.

- **Occupational Therapists (OTs) (via the Intermediate Care Team)**

The OTs will:

- assess your needs; and
- introduce techniques for daily living within your home and with leisure activities.

They will also assess how you move. If appropriate, they will provide you with equipment which may help with this. The OTs can also provide advice on specialist seating and positioning.

- **Occupational Therapy (via Kent Adult Social Services)**

Occupational Therapy will assess your home for major equipment or adaptation needs.

- **Speech and Language Therapists (SLT)**

The SLT will support you and your family, to help you to manage any changes to your communication. They will offer practical help, and make sure that you have other methods of communicating, as needed. This may include a referral to the KMCAT team (see below).

The SLT will assess you for any swallowing difficulties connected with eating and drinking. They will offer you advice on managing your saliva, if needed.

- **Kent and Medway Communication and Assistive Technology Service (KMCAT) Adult Team**

The multidisciplinary team provides a specialist assessment service. The KMCAT team provides communication aids for people needing help with spoken communication.

- **Dietician (Community Nutrition Support Team; Home Enteral Nutrition Team)**

Your dietician will provide the following ongoing support to you and your family.

- Help to cope with any nutritional problems you are having. This could include fortifying your food and arranging nutritional supplements.
- Advice on alternative feeding, if needed.
- Organising equipment, if you need an alternative method of feeding.

- **Environmental Controls Team**

This service loans electronic assistive technology equipment to people. The team covers East Sussex, Kent, and South East London. The equipment allows people to live more independently in their homes.

An environmental control system is electronic assistive technology that can be operated remotely. It allows people to:

- control access to their home
- ask for emergency help
- operate domestic appliances such as the phone, TV, video, and stereo from a central control; and
- switch electrical power for lighting and other appliances.

What is the role of the Pilgrims Hospice?

The Pilgrims Hospice provides specialist palliative care to patients and their carers across east Kent.

Their vision for hospice care is that everyone should have access to the services they need to cope with a life-limiting illness. This may start quite early in your diagnosis, to help with advance care planning. However, you can contact them at any time you feel you need their help or advice. Their aim is to support and empower you, your family, and friends to live well and achieve a good quality of life. This is achieved through the multidisciplinary team who might see you in a Pilgrims Therapy Centre, an outpatient clinic, or your own home.

Their palliative specialist team includes:

- doctors
- nurses
- social workers
- occupational therapists
- physiotherapists; and
- counsellors.

The Pilgrims Hospice also offer spiritual support and access to complementary therapies.

Pilgrims Hospice Inpatient Units

Most patients never need to stay in the inpatient unit. However from time to time, some patients have a short stay at one of the hospices for a specific reason. This could be to get their symptoms under control with a change of medication.

As part of advance care planning, some patients choose to go to their local hospice, where beds are available in the last days of life.

Pilgrims Therapy Centre

The Pilgrims Therapy Centres offer a range of programmes designed to help your wellbeing.

- Therapeutic programmes, which include:
 - gentle exercise programmes; or
 - groups to help you deal with symptoms, such as anxiety, breathlessness, or fatigue (tiredness).
- Creative programmes, which include music and art groups. These can help with specific symptoms, and your overall wellbeing and quality of life.
- Social programmes which provide a chance to:
 - meet and connect with other patients; and
 - gain an understanding of the full range of Pilgrims services that are available.

These popular sessions take place in a relaxed social environment. The sessions can provide practical advice to enable you to keep your independence.

- Education programmes allow you to:

- plan your future care; and
- share your wishes with friends, family, and the healthcare professionals involved.
- Carer programmes. Family and friends play an essential role in supporting patients. Pilgrims' carer groups provide practical, emotional, and social support for carers. This support extends into their bereavement programme too.

Visit the Pilgrims Hospice web site for more information about Pilgrims Therapy Centres and all other Pilgrims services (<https://www.pilgrimshospices.org>). If you feel that any of Pilgrims' services would help you, please talk to your GP or healthcare professional. They will be able to refer you.

Who can make a referral to the East Kent MND Team?

Any of the following individuals can refer you to the East Kent MND Team.

- Your neurologist (specialist in diseases of the nervous system).
- Your GP.
- Other professionals involved in your care.

How are referrals made?

To organise a referral, please contact one of the following members of the MND team.

- **MND Nurse Specialists**
Telephone: 07771 841690 (mobile)
Telephone: 07768 272516 (mobile)

Further information

- **Motor Neurone Disease Association (MNDA)** (<https://www.mndassociation.org/>)
MND Connect Telephone: 0808 802 6262

The Motor Neurone Disease Association (MNDA) is a charitable organisation. It aims to bring together all people concerned with MND. This includes people with the disease, their carers, and healthcare professionals. MNDA uses its funds to support research into the disease and its management. It also supports the care of people with MND. They also offer equipment on loan, where this is not available from local statutory services.

- **MND Association Senior Area Support Coordinator**
Telephone: 0808 802 6262

The **MND Association Senior Area Support Coordinator** will visit people with MND. They provide:

- an independent source of information and advice; and
- work closely with health and social care professionals.

- **The East Kent Group**

This group is part of the MND Association. The group raises funds to support research into the disease and to support local people with MND. It is a group of volunteers that meet regularly to discuss national events and research, and arrange local fundraising events. They organise regular support meetings in a friendly, informal setting that patients, families, and carers can go to. The meetings also include visitors who are volunteers that are aware how MND can affect people. These visitors offer regular contact and personal support. The MND nurse specialists go to the group support meetings.

What do you think of this leaflet?

We welcome feedback, whether positive or negative, as it helps us to improve our care and services.

If you would like to give us feedback about this leaflet, please fill in our short online survey. Either scan the QR code below, or use the web link. We do not record your personal information, unless you provide contact details and would like to talk to us some more.

Giving feedback about this leaflet



<https://www.smartsurvey.co.uk/s/MDOBU4/>

If you would rather talk to someone instead of filling in a survey, please call the Patient Voice Team.

- **Patient Voice Team**

Telephone: 01227 868605

Email (ekhuft.patientvoice@nhs.net)

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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