East Kent Motor Neurone Disease (MND) Multi-Disciplinary Team

Provides support, advice, and help to those affected by MND

Motor Neurone Disease (MND) affects people in many different ways and every person with the disease will be different. Problems will often affect both the person with the disease, 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 in order to reduce the disruption to life as much as possible, so that this can be achieved a confidential meeting is held where the professionals involved can share information, ideas, and experiences to ensure 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, and consists of a MND nurse and various community health professionals, including:

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

The multi-disciplinary team meet every six to eight weeks where they collaboratively discuss each patient known to the East Kent team. At this meeting information is shared so that a seamless service between teams is provided.

The team liaises with the MND Regional Care Centre and Research Centre, 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 and a careful assessment of your condition will be made. Other specialists may be available to provide help and advice from respiratory consultant and palliative care.

MND Nurse
Chrissie Batts is employed by the Trust to support, help, and provide information to those living with MND, their families, and their carers. She will complete referrals to other health and social care professionals for specialist assessment and link up with community therapists so that a co-ordinated approach towards your care is achieved. She will visit you regularly at mutually agreed intervals, dates, and times in your own home and she will be in contact with your GP so that they are aware of the team’s involvement and can share in the team approach to your care. Chrissie is also present at the twice monthly clinic held at WHH.

Physiotherapists (via the Intermediate Care Team)
The physiotherapist will teach you exercises to maintain joint range of movement and ease pain and stiffness. They will provide advice and appliances to help mobility and transfers and activities of daily living and abilities. Good positioning to maintain comfort and reduce problems associated with weakness and joint stiffness and advice on respiratory difficulties.

Occupational Therapists (OT) (via the Intermediate Care Team)
The OTs will assess your needs and introduce techniques for daily living within your home environment and leisure activities. They will also assess how you move and, if appropriate, provide any equipment which may help, as well as providing advice on appropriate specialist seating and positioning.

Occupational Therapy (via Kent Adult Social Services)
They will assess for major equipment or adaptations to your home.

Speech and Language Therapists (SLT)
The SLT will provide ongoing support to you and your family to help you to manage any changes to your communication. They will offer practical strategies and will ensure that you have alternative methods of communicating as needed. This may include a referral to the KM CAT Service (see below). They will assess you for any swallowing difficulties connected with eating and drinking, and offer you advice on managing your saliva if this is required.

Kent and Medway Communication and Assistive Technology Service (KMCAT) Adult Team
The multi-disciplinary team provides a specialist assessment service and communication aids for people needing help with spoken communication.

Environmental Controls Team
This service provides electronic assistive technology equipment, on loan, to people in East Sussex, Kent, and South East London which enables them to live more independently in their homes. An environmental control system is electronic assistive technology that can be operated remotely and enables people to: control access to their home, summon emergency help, operate domestic appliances such as telephone, television, video, and stereo from a central control, and switch electrical power for lighting and other appliances.
Dietician (via the Intermediate Care Team, Community Nutrition Support Team, Home Enteral Nutrition Team)
The dietician provides ongoing support to you and your family to help you cope with any nutritional problems, such as fortifying your food and arranging nutritional supplements. The dietician can also advise on alternative feeding if necessary and organise the provision of equipment if an alternative method of feeding is needed.

What is the role of the Pilgrims Hospice?
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 or at any time you and your health professional feel you need our input. We aim to support and empower you, your family, and friends to live well and achieve a good quality of life. This is achieved though our multi-disciplinary team who might see you in a Pilgrims Therapy Centre, an outpatient clinic, or your own home.

The palliative specialist team includes: doctors, nurses, social workers, occupational therapists, physiotherapists, and counsellors. They also offer spiritual support and access to complementary therapies.

Pilgrims Hospice Inpatient Units
The majority of their patients never need to stay in our 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 symptoms under control with a change of medication. As part of advance care planning, some patients do choose to come in to their local hospice where beds are available in the last days of life.

Pilgrims Therapy Centre
In the Pilgrims Therapy centres we offer a range of programmes designed to help enhance your wellbeing. These include:

• Therapeutic programmes: such as gentle exercise programmes or groups to help you deal with symptoms like anxiety, breathlessness, or fatigue.

• Creative programmes: music and art groups that can help with specific symptoms and overall wellbeing and quality of life.

• Social programmes: a chance to meet and connect with other patients and to gain an understanding of the full range of Pilgrims services available. These popular sessions take place in a relaxed social environment with practical advice to enable you to maintain your independence.

• Education programmes allow you to plan your future care and share your wishes with friends, family, and healthcare professionals involved.

• Carer programmes: family and friends play an essential role in supporting patients. Pilgrims’ carers groups provide practical, emotional, and social support for carers. This support extends into their bereavement programme too.
More information about Pilgrims Therapy Centres and all of our other services is available on our
web site www.pilgrimshospices.org

The Pilgrims Therapy Centre brochure is available on the following link www.pilgrimshospices.org/
wp-content/uploads/Pilgrims-Day-Services-Booklet-A5_WEB.pdf

If you feel you would benefit from any of our services please talk to your GP or healthcare
professional who will be able to refer you.

**Who can make a referral to the East Kent MND Team?**
Referrals to the team can be made by:
- you or your family or carer(s)
- your neurologist (specialist in diseases of the nervous system)
- your GP
- other professionals involved in your care.

**How are referrals made?**
Referrals should be made to:

- **Chrissie Batts, MND Nurse Specialist**  
  Telephone: 07771 841690 (mobile); or

- **Secretary to MND nurse specialist**  
  Tower Neuro Rehab Unit  
  Kent and Canterbury Hospital  
  Ethelbert Road, Canterbury  
  Kent, CT1 3NG  
  Telephone: 01227 868716
Further information

- The Motor Neurone Disease Association is a charitable organisation that aims to bring together all people concerned with MND - people with the disease, their carers, and professionals. Its funds are used to support research into the disease and its management, and support the care of people with MND. They do this by providing information and advice to people with MND, their carers, and to professionals involved in their care, and by offering equipment on loan in cases where this is not available from local statutory services.

  **MND Connect**
  **Telephone:** 0808 802 6262
  **Web site:** [www.mndassociation.org/](http://www.mndassociation.org/)

- The MND Association Regional Care and Development Adviser
  Will visit people with MND, provide an independent source of information and advice, and work closely with health and social care professionals.
  **Telephone:** 07768 197601
  **Email:** cathy.finnis@mndassociation.org

- The East Kent Group
  This is a part of the MND Association who raise 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 attend. It also includes Association visitors who are volunteers that are aware how MND can affect people and offer regular contact and personal support. Chrissie attends both the group meetings and support meetings.
  **Association visitor:** Judy Keay
  **Telephone:** 07580 517533 (mobile)

---

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff.

**Any complaints, comments, concerns, or compliments** please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 or 01227 864314, or email [ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)

**Further patient leaflets** are available via the East Kent Hospitals web site [www.ekhuft.nhs.uk/patientinformation](http://www.ekhuft.nhs.uk/patientinformation)