

East Kent Motor Neurone Disease (MND) Multidisciplinary 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 their 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 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, and includes a 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 six to eight weeks and together they 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 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 and a careful assessment of your condition will be made. Other specialists may be available to provide help and advice.

- **MND Nurses**

Christine Batts and Amy Roberts are employed by the Trust to support, help, and provide information to those living with MND, their family, and their carers. They 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.

They will review you at regular intervals in clinic and occasionally in your own home. They will be in contact with your GP, so that your GP surgery is aware of the team's involvement and can share in the team approach to your care. Christine and Amy 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 positioning when sitting and standing. This will help with your comfort and reduce any problems linked with muscle weakness and joint stiffness. They 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 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 specialist seating and positioning.

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

They will assess your home for major equipment or adaptation needs.

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

The SLT will provide support to you and your family to help you to manage any changes to your communication. They will offer practical strategies and will make sure that you have alternative methods of communicating as needed. This may include a referral to the KMCAT 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 needed.

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

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

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

Your dietician will provide ongoing support to you and your family to help you cope with any nutritional problems you are having, such as fortifying your food and arranging nutritional supplements. Your dietician can also advise you on alternative feeding if necessary and organise equipment if an alternative method of feeding is needed.

- **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 allows people to: control access to their home, ask for 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.

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 their input. 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.

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

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 do choose to come in 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. These include:

- Therapeutic programmes such as gentle exercise programmes or groups to help you deal with symptoms like anxiety, breathlessness, or fatigue (tiredness).
- Creative programmes such as music and art groups that can help with specific symptoms and your overall wellbeing and quality of life.
- Social programmes provide 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 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.

More information about Pilgrims Therapy Centres and all of our other services is available on our web site www.pilgrimshospices.org 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?

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

- **Chrissie Batts, MND Nurse Specialist**
Telephone: 07771 84 16 90 (mobile)
- **Amy Roberts, MND Specialist Nurse**
Telephone: 07768 27 25 16
- **Kay Shaw (Secretary to the MND nurse specialists)**
Working hours: Monday, Wednesday, and Friday 8:30am to 2:30pm
Tower Neuro Rehabilitation Unit
Kent and Canterbury Hospital
Ethelbert Road
Canterbury CT1 3NG
Telephone: 01227 86 87 16

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 8 02 62 62

Web: www.mndassociation.org/

- **The MND Association Senior Area Support Coordinator** will visit people with MND, provide an independent source of information and advice, and work closely with health and social care professionals.

Telephone: 0808 8 02 62 62

- **The East Kent Group**

This group is part of the MND Association and 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. It also includes Association visitors who are volunteers that are aware how MND can affect people and offer regular contact and personal support. Chrissie and Amy both go to the group support meetings.

Association visitor: Judy Keay

Telephone: 07496 41 78 41 (mobile)

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation