Patient and Carer Guide
What is the South Wales MND Care Network?

The South Wales Motor Neurone Disease (MND) Care Network has been established with funding in collaboration between the MND Association and the NHS.

The aim of the network is to:
- Improve the care for people with MND.
- Improve access to care for people with MND.
- Reduce the inequity in care across South Wales for people with MND.

The network team includes:

Co-Directors:
- Dr Idris Baker MA FRCP, Consultant in Palliative Medicine
- Dr Kenneth Dawson MB BS FRCP, Consultant Neurologist
- Dr M Wardle MD FRCP, Consultant Neurologist
- Dr C Hirst MBBCh MD MRCP (Neurology), Consultant Neurologist

Network Care Co-ordinators:
- Ruth Glew – Lead Care Coordinator
- Katie Hancock – South East Wales Care Coordinator
- Caroline Bidder – South West Wales Care Coordinator
- Stephanie Durnan – South East Wales Care Coordinator

Network OT’s:
- Sara Mallams – Network OT for South West Wales

MNDA Regional Care Development Advisor:
- Carol Smith
Your care team

After being diagnosed with MND you are likely to have contact with a number of different professionals. At times this may feel overwhelming. It is important that you feel able to communicate how you feel and that you are involved in decision making about your care. Your care co-ordinator will play an important role in assisting you with decision making and helping with organisation of your of care. You will be seen regularly at clinic, or at home by members of the team if you are unable to get to the clinic.

The Role of the MND Care Co-ordinator:

The MND co-ordinator will provide you with support and information at the time of diagnosis and ensure that you receive the care you need in a timely manner.

Who will I see at clinic? – The MND Clinic Team:

At clinic you will be seen by a Consultant Neurologist with a special interest in MND. You will also see the Care co-ordinator and individual therapists as needed:

Physiotherapy - The Physiotherapist advises on exercises and stretches to maintain flexibility and prevent stiffness and pain caused by immobility. They can also assess the need for aids to support posture and walking.

Occupational Therapy (OT) - The OT assesses your ability to perform tasks and gives advice on techniques, equipment and home adaptation to promote and maintain independence. Usually we will arrange for a community therapist to be involved with your care.
Palliative Care – the Palliative Medicine Consultant can advise on symptom control and pain relief. The Palliative Care team will help you plan your future care.

Speech and Language Therapy (SLT) - The Speech and Language therapist advises patients and carers on how to maximise speech and swallowing function. They can also suggest alternative forms of communication.

Dietetics – The dietician provides assessment of nutritional status and review of dietary intake. Diet, nutritional supplementation and alternative feeding requirements are assessed in conjunction with the SLT.

MND Association Visitor – The Association Visitor (AV) is a volunteer who greets you at clinic and can give information about the MND Association and provide support if required.

MND Care Team

There are several other professionals who may be involved in your care at various stages such as:

Primary Care team – (GP, District Nurse, Chronic Conditions Nurse), assist in coordinating your everyday care at home.

Respiratory team – your breathing will be assessed regularly at clinic. Should you have any problems, you will be referred to your local respiratory services for advice and management.

Gastroenterology team – your swallowing and nutrition will be assessed at clinic. Should you have any problems you will be referred for discussion of available options to help with maintaining your nutritional status.
Social Worker – will assess your practical care needs and negotiate the most appropriate way of meeting them. This includes both yourself and your carer, if you have one.

Your care will be discussed by the professionals involved at regular multi-disciplinary team meetings to ensure your needs are met in a timely manner.

What will happen when I am referred to the South Wales MND Care network?

You will receive a visit from your care co-ordinator who will discuss your current situation and answer any questions you may have. You will be offered contact with the MNDA whose services are outlined at the end of the leaflet.

Following this you will be offered a clinic appointment at your local MND Multidisciplinary team clinic. If you are unable to attend a clinic, your care will be coordinated via the clinic team and you will receive visits from your local services.

Sharing of information

Information about you and your medical condition will be shared at multidisciplinary team clinics and meetings where your care is co-ordinated with NHS and social service staff.

Staff from the Motor Neurone Disease Association (MNDA), such as the Regional Care Development Advisor and Association Visitors and also other voluntary agencies such as hospice care may be involved in your care. In order for us to provide you with timely and effective care, it may be helpful for us to be able to share your personal details, as well as details about your medical condition. In this situation we would always ask for your explicit consent to share any information.
Multidisciplinary MND Clinics

- **Bridgend Clinic** - 1st Thursday of the month (3 monthly) (pm)  
  Dr R Walters/Dr P Grzybowska/Dr J Wooley - Maesteg Hospital, Maesteg.

- **Cardiff (Whitchurch) Clinic** - 2nd Monday of the month (pm)  
  Dr A Lowman - Whitchurch Hospital, Cardiff.

- **Cardiff (Penarth) Clinic** - 4th Monday of the month (pm)  
  Dr P Stewart – Holme Towers, Penarth.

- **Cardigan Clinic** - 3 monthly (am)  
  Dr C Hirst – Cardigan and District Hospital, Cardigan.

- **Carmarthen Clinic** - 3rd Monday of the month (am)  
  Dr C Hirst/Dr R Croft - Glangwilli Hospital, Carmarthen.

- **Cwm Taf Clinic** - 3rd Monday of the month (am)  
  Dr M Wardle - Ysbyty Cwm Cynon, Mountain Ash.

- **Gwent Clinic (North)** - 2nd Monday of the month (am)  
  Dr K Dawson/Dr M Williams - Ysbyty Aneurin Bevan, Ebbw Vale.

- **Gwent Clinic (South)** - 2nd Friday of the month (am)  
  Dr K Dawson/Dr D Jenkins/Dr S Fairbairn - St David’s Hospice, Newport.

- **Neath Port Talbot** - 2nd Thursday of the month (pm)  
  Dr S Hadjikoutis/Dr S Morgan - Neath Port Talbot Hospital, Port Talbot.

- **Swansea Clinic** - 1st Tuesday of the month (pm)  
  Dr S Hadjikoutis/Dr I Baker - Morriston Hospital, Swansea.

We ask that you bring details of your current medication, communication aid (if you have one) and glasses/hearing aid (if required) to clinic appointments.
Motor Neurone Disease Association

The MND Association exists to ensure people with MND and those who care for them are able to access the best care and achieve the highest possible quality of life. There are several sources of support:

**MNDA Association Visitors:**
Offer free and confidential emotional support, and information about the Association and other services that help you make informed choices.

**Local Branches and Support Groups:**
Provide a friendly opportunity to meet others affected by MND. They offer advice and support, including newsletters and regular meetings. You can find out about your local branch by contacting MND connect.

**MND Connect:**
MND Connect is a telephone helpline offering you access to advice, practical and emotional support and direction to other services and agencies. This service is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays. Calls charged at local rate.

![MND Connect Logo](https://example.com/mndconnect.png)

**Regional Care Development Advisor:**
The MNDA Regional Care advisor works with local health and social care staff to improve services for people with MND. He/she can provide information and advice to you and the health and social care professionals involved in your care, and ensure you receive the support you need.
Your regional Care Development Advisor is:
Carol Smith, Tel: 03453-751853
**How do I contact the Network?**

For questions or queries regarding any aspect of MND care, please contact the MND Care Centre Co-ordinator in your area:

**Ruth Glew - MND Network Lead Care Coordinator**  
(Mon - Fri, 8am – 4pm).  
Tel: 01792 703705 or 02920 313828

**South West Wales:**  
*Based at Ty Olwen, Morriston Hospital, Swansea, SA6 6NL*

**Caroline Bidder** – South West Wales Care Coordinator  
(Mon, Tue & Thurs, 8am – 4pm).  
Tel: 01792 703705  
Email: abm.southwestwalesmnd@wales.nhs.uk

**Sara Mallams** – South West Wales Network OT  
(Tuesday, 8.30am – 4.30pm).

**South East Wales:**  
*Based at Rookwood Hospital, Fairwater Road, Cardiff, CF5 2YN*

**Katie Gibbon** – South East Wales Care Coordinator  
Care Coordinator  
(Mon – Wed, 8am – 4pm & Thurs am).  
Tel: 02920 313828  
Email: southeastwales.mnd.cav@wales.nhs.uk

**Stephanie Durnan** – South East Care Coordinator

As the network co-ordinators are often out of the office please leave your name and daytime telephone number should you get an answer phone message and we will get back to you as soon as possible. Alternatively, you can visit our website at:  
[www.mnd.wales.nhs.uk](http://www.mnd.wales.nhs.uk)

**The MND network cannot provide emergency assistance.**
- For urgent problems or queries relating to your symptoms please contact your GP/ primary care team,
- For urgent queries regarding MND generally please contact MND connect if the network team are unavailable