South Wales Motor Neuron Disease Network

Alison Fleming / Sian Vincent

Motor Neuron Disease

Care Coordinator - South West

Patient Journey - From Diagnosis

- ► Patient is diagnosed by the Consultant Neurologist
- Consultant Neurologist refers the patient to the MND Network
- Care Coordinator visits patient to carry out an Initial Assessment to find out background information and presenting symptoms of MND
- Initial Assessment is shared with the MDT and patients GP
- Dependent on presenting symptoms, Care Coordinator will refer on to appropriate Professionals
- Care Coordinator will arrange for patient to be reviewed at an MND Clinic

Swansea & NPT Clinic MDTs

- Care Coordinator Alison Fleming
- Consultant Neurologist Dr Karthik Nagaraj (Swansea)
- Consultant in Palliative Care Dr Idris Baker
- Respiratory Consultant Dr Tarek Dihan
- Specialist Respiratory Nurse Jodie Riggs
- Specialist Physiotherapist Richard Pawsey
- Specialist Dietitian Adrienne Tunna
- Specialist Speech and Language Therapist Hannah Broadhurst (Swansea)
- Specialist Speech and Language Therapist Sarah Brown (Swansea)
- ► Specialist Speech and Language Therapist Nicola Cole (NPT)
- Specialist Speech and Language Therapist Kiyana Burgess (NPT)

Carmarthen Clinic MDT

- Care Coordinator Sian Vincent
- Consultant Neurologist Dr Karthik Nagaraj
- ► SPC Consultant Dr Rebecca Croft
- Respiratory Clinical Nurse Specialist Joe Annandale
- Specialist Physiotherapist Katie Phillips
- Specialist Occupational Therapist Claire Thomas / Kathryn Furlong
- ► Specialist Speech & Language Therapist Sarah Davies / Alison Thomas
- Specialist Dietitian Paul Makin
- Nutrition Clinical Nurse Specialist Nadine Hughes-Llewellyn / Linda Broomfield

Patient Journey - Clinic

- ► A Pre Clinic meeting is held in order to discuss the patients who will be attending
- ► When the patient attends the MND Clinic they will be seen and assessed by all members of the MDT
- ► The Specialist Respiratory Nurse will carry out specific respiratory tests
- ► Each Professional will arrange to carry out interventions as appropriate, or refer on e.g. if orthoses are required
- ► Following Clinic a Post Clinic meeting is held to discuss interventions and any concerns regarding the patients who have attended
- ► The patient and their GP will be sent a copy of the Clinic Review

Patient Journey - Ongoing

- ► Each patient is seen at least once every 3 months at an MND Clinic
- ► Patients are often seen far more frequently by members of the MDT who will carry out home visits as and when needed
- ► The Care Coordinator is the main contact between the patient and the MDT (we encourage patients to contact us as needed)
- ► The MDT will notify the Care Coordinator of all contacts and interventions that are carried out in order for them to be recorded on the Patient Care database
- ► The progression of MND varies widely and can be very rapid, generally life expectancy from onset of initial symptoms is between two and five years