Picture: member of the Cleveland Branch ‘MNDA Hi 5’ campaign which include tributes and messages of support for friends and family who have been affected by the disease.

Produced by:
Anthony Hanratty
Motor Neurone Disease Nurse and Care Coordinator
Middlesbrough MND Care Centre
South Tees Hospitals NHS FT – Tertiary Services Centre
August 2014
Contents

Summary 2

1. Background 2-3
   1.1 Middlesbrough MND Care Centre 3-5

2. Activity 2013/2014 6
   2.1 Patient figures by month 6-7
   2.2 MDT working – Figures by month 7-8
   2.3 MDT team clinic 8-10
   2.4 Advice line 10-12

3. Service Development 13
   3.1 Butterwick Neurological First Contact Group 13-15
   3.2 Palliative care 15-16
   3.3 Community MDT’s 16-17
   3.4 Website/intranet 17
   3.5 Audit and survey 18-19

4. MND service 2014/15 20-21

5. Constraints/pressure on work 22

6. Distribution list 23

Appendix 1: MND Nurse & Care Coordinator basic job plan 24
Summary
This report serves as a reflective review of annual activity, progress made, challenges encountered and development opportunities within the last 12 months of the Motor Neurone Disease (MND) service. It will give information, activity and data relating to that collated by the MND Nurse and Care Coordinator from 1st August 2013 – 31st July 2014. It relates only to activity carried out and referrals made to or by the MND Nurse and Care Coordinator and do not include referrals which may have been made by other members of the MND Multidisciplinary Team (MDT).

1. Background
MND is a rare neurological condition, characterised by progressive degeneration of the motor neurones in the brain, brain stem and spinal cord, resulting in weakening and wasting of the associated muscles. It affects both the upper and lower motor neurones, leading to loss of mobility, difficulties with speech, swallowing and breathing. Disease progression is rapid, with average life expectancy of between 2 and 5 years from symptom onset. Approximately 10% of people diagnosed with MND will live for more than 10 years.

MND is an umbrella term used to describe variants of the disease – namely, Amyotrophic Lateral Sclerosis (ALS), Progressive Bulbar Palsy (PBP), Progressive Muscular Atrophy (PMA) and Primary Lateral Sclerosis (PLS). ALS is the most common form of MND, which according to NICE (2001) accounts for 65% to 85% of all cases. Symptoms of the disease include weakness, tripping/stumbling, slurring of speech, muscle wasting, fasciculation’s and fatigue, which ultimately leads to a reduction in life expectancy and early death usually due to associated respiratory complications.

- MND can affect any adult at any age, but is most common in ages 50-70 years of age.
- It affects more men than women with a ratio 2:1.
- Incidence of MND is 2 in every 100,000 of the population.
Prevalence of MND is approximately 5-7 in every 100,000 of the population.

1.1 Middlesbrough MND Care Centre
Middlesbrough MND Care Centre is one of 19 specialist care centres & networks specifically set up to improve the standards of care for people with MND. It is a sub-regional centre which aims to be:

- A single point of contact for all persons affected by or caring for a person with MND
- Provide expertise in the management of MND
- Create links with community teams in order to provide excellent services for people with MND
- Provide education, share good practice and be a centre for information sharing for persons with MND, carers and health professionals.

With a total population of approximately 1 million, it covers the CCG areas of:
- Durham Dales, Easington & Sedgefield,
- Darlington,
- Hartlepool & Stockton-On-Tees,
- South Tees,
- Hambleton, Richmondshire & Whitby

Serving a further 1.1 million people, It also takes referrals from the CCG areas of:
- Harrogate and Rural District,
- Scarborough and Ryedale,
- Vale of York,
- North Durham
- Sunderland

With an individual shared care agreement with the respective neurology/GP teams in those areas.
The care centre is MDT led and overseen by a consultant neurologist with a special interest in MND. Below is a list of the primary team members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Janine Evans</td>
<td>Consultant Neurologist &amp; Care Centre Director</td>
<td>Varied</td>
</tr>
<tr>
<td>Anthony Hanratty</td>
<td>MND Nurse &amp; Care Centre Coordinator</td>
<td>Full time</td>
</tr>
<tr>
<td>Sue Gavaghan</td>
<td>Physiotherapist</td>
<td>Clinic only</td>
</tr>
<tr>
<td>Becky Jordan</td>
<td>Occupational Therapist</td>
<td>2 days</td>
</tr>
<tr>
<td>Emma Wood</td>
<td>Dietitian</td>
<td>1½ days</td>
</tr>
<tr>
<td>Gill Everson</td>
<td>Speech &amp; Language Therapist</td>
<td>MND clinic and home visit availability (2 sessions)</td>
</tr>
<tr>
<td>Stephen Evans</td>
<td>Neuro-psychologist</td>
<td>Half day/own clinic</td>
</tr>
<tr>
<td>Colin Pearson</td>
<td>Regional Care Development Advisor</td>
<td>Full time</td>
</tr>
<tr>
<td>Jenny James</td>
<td>Regional Care Development Advisor</td>
<td>Full time</td>
</tr>
<tr>
<td>Jane Pearson</td>
<td>Audio Typist/Clerical Officer</td>
<td>1 day</td>
</tr>
</tbody>
</table>

The MND team currently have a caseload of 77 patients (as at 31.7.14). This gives a prevalence of approximately 7.7 in every 100,000 of the local population living with MND at this time, with an average of 8.1 in every 100,000 of the local population living with MND this year.

The tables below demonstrate the figures for patients currently under the care of Middlesbrough MND Care Centre.

<table>
<thead>
<tr>
<th>CCG</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Durham Dales, Easington &amp; Sedgfield</td>
<td>9</td>
</tr>
<tr>
<td>Darlington</td>
<td>7</td>
</tr>
<tr>
<td>Hartlepool &amp; Stockton-on-Tees</td>
<td>16</td>
</tr>
<tr>
<td>South Tees</td>
<td>25</td>
</tr>
<tr>
<td>Hambleton, Richmondshire &amp; Whitby</td>
<td>18</td>
</tr>
<tr>
<td>Other CCG areas</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>77</strong></td>
</tr>
</tbody>
</table>

### Age range of current patient case load

<table>
<thead>
<tr>
<th>Age range of current patient case load</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>0</td>
</tr>
<tr>
<td>26-35</td>
<td>0</td>
</tr>
<tr>
<td>36-45</td>
<td>6</td>
</tr>
<tr>
<td>46-55</td>
<td>8</td>
</tr>
<tr>
<td>56-65</td>
<td>27</td>
</tr>
<tr>
<td>66-75</td>
<td>23</td>
</tr>
<tr>
<td>76+</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>77</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>50</td>
<td>27</td>
<td>77</td>
</tr>
</tbody>
</table>

From August 2013 – July 2014 there were a total of 39 new referrals made to the MND service. Of these, 37 were newly diagnosed with MND and 2 transferred their care from another care centre. This gives an incidence of approximately 3.7 people being diagnosed in every 100,000 of the local population this year.
2. **Activity 2013/2014**

2.1 Patient figures by month

![Graph showing total number of patients known to care centre at month end 2013/14](image)

![Graph showing total number of patients known to care centre 2012/13 and 2013/14 comparison](image)

![Graph showing MND patient mean yearly trend](image)
2.2 MDT working – figures by month

**Total number of referrals and deaths 2013/14**

![Chart showing total referrals and deaths by month]

**Direct patient contact**

![Chart showing direct patient contact by month]

**Multidisciplinary service referrals**

![Chart showing referrals by month]

2.3 MDT team clinic

The MND team clinic is held every Wednesday in the Neurosciences Outpatient department at The James Cook University Hospital, Middlesbrough.

Once patients have had a diagnosis of MND given by their referring consultant, they are initially invited to Dr Evans general neurology clinic, usually within 2 weeks of their initial diagnosis in-line with the MND Association standards of care. This initial clinic visit allows the patient to have an extended clinic appointment on a one-to-one basis with Dr Evans in an unhurried setting enabling them to ask any questions they may have, address any concerns and for family or carers to have their questions answered. It allows for Dr Evans to confirm the diagnosis of MND, offering the patient a second opinion and if appropriate, organising onward investigations, assessments or referral to appropriate health and social care professionals. Dr Evans at this point is also able to introduce, if appropriate, treatment options, begin discussions around advance care planning and invite the patient to the MND MDT clinic within the next 2-4 weeks.

The MND MDT clinic offers the patient the opportunity to have a holistic assessment carried out by the entire MND team in one clinic setting, preventing the need for re-attendance at individual clinics.
Overwhelmingly, our patients tell us that the way we currently give a diagnosis, the follow up with Dr Evans in her general clinic followed by attendance at the MND MDT clinic is appropriate, with 94% of those responding to our most recent patient satisfaction survey expressing they were given their diagnosis in a dignified, sensitive and caring manner. Patients express the clinic setup is right for their needs with one patient commenting in our most recent patient satisfaction survey that:

“There is always a good atmosphere when I’m there, which makes what people are saying easier to absorb”

…and another expressing:

“All members of the team listen to your opinion and views and take your feelings / future wishes into account. They are helpful supportive and care about individuals – it never feels like this is ‘just a job’

<table>
<thead>
<tr>
<th>MND Multidisciplinary Team Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jun</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>10</td>
</tr>
</tbody>
</table>

Number of patient seen in MND clinic

Number of MND MDT clinics
However, we do recognise that the available space is often a concern for some of our patients, which is something the team has previously and continues to work to rectify in the best interest of our patient group, with one patient commenting:

“Rooms at clinic a bit cramped meaning that I cannot always see everyone from my wheelchair.”

2.4 Advice line

In 2012 the RCN updated its guidance on developing a telephone advice line for people with long term conditions (Using telephone advice for patients with long-term conditions: an RCN guide to using technology to complement nursing practice, RCN 2012). Using this guidance and listening to our patient group, our advice line continues to be available for all patients, families, carers and healthcare professionals to access and is available Monday to Friday 9.30am – 2.30pm. The advice line is accessed in 3 ways, to suit our patients needs including by telephone with an answer machine taking messages when the care coordinator is not available/not in the office to answer calls immediately, email or text message.

The care coordinator aims to respond to all calls/messages within 2 working days, with calls and emails being diverted to another appropriate MND team member when the coordinator is on annual leave/away for extended periods of time. The care centre now has a dedicated email account for all patients, family members, carers and health care professionals to contact, removing MND Nurse & Care Coordinator 2013-2014 Annual Report August 2014
the added stress for our patients of having to know or find the contact details of individual team members.

Below is an indication as to the activity experienced throughout the report period in relation to the advice line, also shown is none patient related activity which comes through the advice line, an example of which is that of arrangement of teaching sessions, administrative and management, information/updates, however, this is a non-exhaustive list.

**Key:**

LEVEL 1 – No further action required
LEVEL 2 – Minimum action required. I.E checking patient info, responding to one email or phoning one other person/may require returning patient/care/family/H&Sc call. +/- changing a person’s clinic appointment.
LEVEL 3 - Action requires 2-3 emails to be sent or phoning 2-3 other people
LEVEL 4 – All of the above and/or needing to send 4+ emails or ring 4+ people. Requires action to send a service provider out to that person. Or input a service.

Comparison of total number of contacts to MND advice line 2012/13 and 2013/14

MND advice line - patient activity
2012/13 and 2013/14 comparison

MND advice line - none patient activity
2012/13 and 2013/14 comparison
3. Service development

Throughout this year, the focus of the MND team has been around service development, with a wide range of progresses made enhancing the services available to our patients. This has included the development of new services and also through developing links and partnerships, enhancing services which had either been in development or through assisting teams, have progressed services, improving the overall quality of services available to our patients. Throughout the year we have listened to our patients, other health and social care professionals and also looked at what other MND care centres and other specialties are doing and taking from them the positives, bringing these back to our care centre and making change.

We are also trend setting at Middlesbrough care centre: The development of the Butterwick Neurological First Contact Group is just one of our partnership developments which have been extremely successful and unique certainly to this area. It has caught the imagination of other hospices not only in our immediate area but areas in other regions too who are looking to transform traditional hospice services, moving away from the standard day-care model.

As well as this, the MND team have worked to develop the care centre directly from team education, ensuring our own practice remains up to date to include and involving other professionals, peers and patients living with MND to assist us in delivering an improved service; showing us how we can do things better either through the form of a steering group, team MDT’s, one-to-one, through survey/audit and by inviting others to join us in clinic.

3.1 Butterwick Neurological First Contact Group

The Butterwick Neurological First Contact Group (BNFCG) is a unique, innovative service available for patients with MND from wherever they live within our catchment area. It is hosted by Butterwick Hospice on a Friday afternoon with the aim of;

- Supporting and introducing patients to the hospice setting who would not of otherwise accessed or who did not meet the criteria for traditional hospice care, including day-care and respite care
- Supporting those who did not access support from services such as that of social groups, health and social care agencies or other charitable organisations,
- Supporting those whose MND was relatively stable over a long period of time, often people who continued to work or live a full active social life
- Enabling those who traditionally were not able to access free complementary therapies, psychological support and family therapies to experience the symptomatic relief these can provide.

In general the group of patients this service is aimed at, it is recognised, are less likely to be involved with advance care planning, interaction with palliative care and hospice services, are not likely to mix with other people with a neurological condition and so become isolated in this respect, however by introducing them to a service which enabled them to have an active treatment, to be proactive and be in control of their MND, it was recognised it would allow them to be less frightened of services such as that provided by palliative and associated services, would allow them to access and be supported earlier, symptoms would be better controlled and a proactive approach to interventions, including early discussion around advance care planning could be implemented.

A partnership was developed between the MND care centre, Butterwick Hospice and the MND Association initially from April – July 2013, giving the success of the initial pilot, a yearlong pilot was agreed beginning from August 2013, with added support from the MND Association Cleveland Branch who agreed to fund a further complementary therapist for the yearlong pilot, allowing more patient’s to receive the benefits of this service.

A patient satisfaction survey was carried out following the end of the initial yearlong pilot. As indicated from the survey, patient feedback and the growing number of patients attending the service it is evident this type of approach to meeting needs of those with MND now and in the future is required and is successful. It was found during the pilot that a large aspect of the group was self-management and peer support, which for many has had a major impact.
on individual wellbeing and positive health. It can be argued that many of those who attend this service have deteriorated at a slower rate than expected had they not been attending, although a study looking at this is recommended to look at the impact this service is truly having on individuals and the group as a whole compared to that of those not attending.

Following the very successful year long trial, ending in July 2014, Butterwick Hospice have committed to continuing this service on into the future for the benefit of those with MND, whilst working alongside the care centre and MND Association and a further commitment from the MND Association local branch of another years funding of complementary therapy.

However, due to the success of this service, there is currently an over subscription of patients attending and therefore alternative funding is being sought to extend the service into the morning session also.

3.2 Palliative Care
The MND team and MND Association are working closely with the palliative care services within the local area to improve the way our patients are seen, treated and followed up both in the community and hospital settings.

Working with Fiona Perry, palliative care clinical lead in the South Tees area we are developing links and working relationships with all community and hospital based palliative care teams. The main aim is to ensure all our patients receive equitable care and treatment where ever they are within our catchment area but also to ensure our patients are represented at every level, are included when decisions are made about new developments including pathways and strategies, whether this is at a local or national level.

In the South Tees area, Fiona and her team have developed a new and exciting service which allows rapid access for all patients with a terminal condition to access right from diagnosis, allowing patients to be seen at any point within their disease process. This allows our patients to feel and be supported more quickly and more readily by experienced practitioners who have an increased knowledge of a multitude of diseases but by working
directly with us, as the care centre, allows both our teams to be up skilled in each other’s disciplines, gaining a greater understanding and skill to better understand and assist our patients in a more individualised way.

By getting this right firstly within the South Tees area allows this model to be transferred to other areas, which Fiona, the care centre and RCDA’s from the MND Association are working towards by meeting with other teams with the aim of understanding how their services currently work and secondly how we as a partnership can develop both services to better work together in the best interests of our patient group. This is an on-going development which will continue into the next report year.

3.3 Community MDT’s
The care centre team is always looking for alternative ways of communicating with community teams who care for patients in their own homes. Often it is difficult knowing exactly who is involved with each individual patient and particularly difficult communicating between teams any changes related to individual patients.

The MND Association advocate community MDT’s and have produced a guide (Multidisciplinary team working: a best practice guide MNDA 2011) to assist in the development of these. Given the large number of areas the care centre covers it was important that we get our community MDT’s right, ensuring it meets the needs of our patients and fulfils the needs of the health and social care professionals who will be attending these, meeting the specific aims of:

- An opportunity for professionals to discuss significant patient and professional related issues
- Increased awareness of roles and responsibilities
- Increased cross boundary working
- Increased education, teaching, awareness and peer support
- Improved service links and referral processes
- Enhancement of quality in care provided to patients with MND
- Locally agreed aims specific to that area to be agreed
As a result, a trial area was selected for the MDT and working together with Jenny James from the MND Association the first community MDT in Darlington was successful in bringing together a wide range of professionals. As a result from this, there has been an improvement in the way the care centre interacts and communicates with professionals in the Darlington area, the referral processes have been significantly improved, particularly with regards to occupational therapy and hospice and the group and wider professionals as a result have been able to communicate more effectively and more quickly, resulting in patients having better quality care in that area.

A second trial area has been agreed in the North Yorkshire area, looking at a larger geographical area with greater numbers of patients and professionals involved presents different issues to developing an MDT, but by developing those in these two specific areas will allow the care centre to role the MDT’s out in all areas successfully in the future.

3.4 Website/intranet
In the last report year, the care centre had developed a care centre website, allowing patients, carers and families access to information and resources. Over this report year the website has grown and will continue to grow over the next report year with the vision to include information for health and social care professionals, articles and updated information of interest to our patient group and also copies of reports, results and any other work the care centre has carried out which pertain to our patients.

The care centre team have also developed an intranet site which is available for all South Tees Hospitals NHS Foundation Trust (The Trust) staff to access on internal computers. This gives more information appropriate to health and social care staff, including pathways, referral forms and information related to MND. Currently this site is not available to professionals outside of The Trust; however, with the development of the internet site, we would envisage this information to be available to a wider professional audience in the future.
3.5 Audit and survey
The MND care centre carried out its first patient satisfaction survey. 46.15% of those sent the survey, returned this to us and provided very useful feedback for the MND care centre to both feel extremely positive that we are caring for and managing our patient group in a way which they feel is appropriate to their needs, but also there are a number of areas which can be improved and as a team we have already taken steps and will continue to work to make improvements.

It was encouraging to see that many more of our patients are reporting being directly referred to a neurologist as a first point referral, indicating that our work with local GP’s, nursing and therapy teams is making more people more aware of the first signs of MND. However, there are still patients who tell us they continue to be referred to other specialties and have to return to their GP’s several times before having a neurology referral. With the use of the MND Association ‘Red Flag Tool’ we will continue our work on raising awareness, with the aim of reducing the time between referral and diagnosis.

Our patients continue to tell us that they are given their diagnosis in a way which is sensitive, caring and dignified and in a setting which is appropriate to the sharing of bad news. They feel the person giving the diagnosis is the most appropriate person and the information they receive is relevant and individualised to them. We will continue to encourage this with every patient we give a diagnosis to and share our good practice with others.

Patients tell us they can make contact with the MND care centre easily in various ways with over 94% of those surveyed expressing they know how to make contact if they needed to. Patients also tell us the way we communicate with them is appropriate to their needs and feel they receive the advice, support, information and onward referrals as appropriate. However, we recognise that there continues to be a small number of our patients with whom we do not communicate effectively with or with whom we do not support in a way which they feel is appropriate and therefore we will work to ensure patient care plans are more individualised and look at alternative ways
of communication, which may be more appropriate to our diverse group of patients.

Of those patients who attend the MND MDT clinic, overwhelmingly they tell us they feel the clinic is well run; they feel the clinic setup is appropriate and importantly they feel the clinic team respect, listen and treat each patient individually, including and allowing them to make decisions about their own health. As a team we are aware of the limitations of the clinic setting, including the size of the rooms and the number of patients which can be reviewed on a weekly basis, however, there have been steps taken to rectify this and as a team we will continue to look at this in the future as the changing needs of our patients demand. A number of patients also noted within the survey they weren’t aware of the information available in clinic, we will work to make this information more accessible and available to all our patients.

A re-audit of our Riluzole guidelines has shown an overall improvement from the previous year’s result, indicating that patients who are prescribed Riluzole in our catchment area, are monitored more effectively, with more GP’s using and following the locally agreed Riluzole shared care guidelines. Patient’s safety as a result is improved, with less risk of complications from taking this medication. We do recognise however that there continues to be a number of patients who do not have regular blood tests taken, usually at months 2 and 3. As a result the care centre has put steps in place, through the use of a database to monitor when patients were commenced Riluzole and at what point they are due bloods. The care coordinator then reminds GP’s and patients that their bloods are due and therefore no patient should miss their required blood monitoring date.
4. MND service 2014/15

The MND service in the next report year will focus upon the re-application process to the MND Association and commissioners for the continuation of the Middlesbrough MND Care Centre.

The process will involve and include the application of the currently funded posts of:

- Nurse & care coordinator
- Dietitian
- Neuropsychologist

As well as continue those posts funded through South Tees Hospitals NHS Foundation Trust:

- Consultant neurologist
- Physiotherapist
- Speech & Language Therapist
- Audio Typist/Clerical Officer
- Occupational Therapist (clinic only)

The current occupational therapy role is jointly funded by the MND Association and South Tees Hospitals NHS foundation Trust. Moving forward we will continue to have an occupational therapist as part of the weekly MND MDT clinic to ensure our patients receive input from a highly skilled therapist, whilst also working with the MND Association to look at incorporating part of this occupational therapist role into an exciting and unique role which takes into account the needs of our patient group within our particular catchment area now and in the future.

This role will endeavour to take each individual patient and holistically assess their needs, including but not exclusive to their physical, emotional, spiritual and mental health needs with the aim of working directly with patients and health and social care professionals to keep patients healthy for as long as possible in their preferred place of care, aiding self-help programmes, preventing acute hospital admissions and through working with community practitioners; educating and raising awareness this role will, along with the
rest of the care centre team, allow our patients to feel more supported, have greater quality of life and be more in control of their MND.

In 2014/15 we will also:

- Continue to raise awareness of MND and through education, raise standards of care for our patient group.
- Work with other specialties, namely: palliative care, PEG service and respiratory to improve services for our patient group.
- Create closer working relationships with our community practitioners in the form of MDT’s or working partnerships.
- Work towards developing research at a local level.
5. **Constraints/pressure on work**

- As reported in the previous year’s report, the number of hours of admin support for the MND care centre was reducing from 15 hours, over a 3 day period to 7.5 hours over a 1 day period. Giving the nature of work, the number of contacts made to the care centre from patients and other professionals, and the amount of admin work produced, It was felt at that time that this reduction in hours would lead to a drop in quality of service. This has been the case, with a number of patients commenting to team members that they have found it more difficult to make contact with the care centre team than they had previous, with more patients noting they are needing to leave voice messages when calling than they did previous as an example. The number of contacts made to the care centre has reduced as evidenced in section “2.4 advice line” for which it can be argued is as a direct result of not having admin support to be available to assist in taking calls which come through to the advice line – particularly for those who do not leave voice messages. The MND team feel it is imperative for the quality of our service and for the benefit and quality of our patients that admin support is available and all patients and health and social care professionals are able to make contact.
Distribution list

- **Dr J Evans**, Consultant Neurologist, Middlesbrough MND Care Centre Director
- **Sue Gavaghan**, Physiotherapist, Middlesbrough MND Care Centre
- **Emma Wood**, Dietitian, Middlesbrough MND Care Centre
- **Becky Jordan**, Occupational Therapist, Middlesbrough MND Care Centre
- **Gill Everson**, Speech & Language Therapist, Middlesbrough MND Care Centre
- **Stephen Evans**, Neuropsychologist, Middlesbrough MND Care Centre
- **Jane Pearson**, Audio Typist/Clerical Officer, Middlesbrough MND Care Centre
- **Steve Bell**, MND Association (Northern Region)
- **Sue Geldart**, Managing Director, Tertiary Services Centre, JCUH
- **Lucy Tulloch**, Directorate Manager, Neurosciences, JCUH
- **Sharon Poskitt**, Head of Nursing, Tertiary Services Centre, JCUH
- **Dr P McKee**, Consultant Neurologist, Clinical Director Neurology
- **Colin Pearson**, RCDA, MND Association
- **Jenny James**, RCDA, MND Association
- **Carol Bell**, Ward Manager, Ward 25 (Neurology), JCUH
- **Ruth Holt**, Director of Nursing, JCUH
Appendix 1 - MND Nurse & Care Coordinator basic job plan

<table>
<thead>
<tr>
<th>Day</th>
<th>Morning</th>
<th>Afternoon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>Telephone reviews/admin</td>
<td>Service development (audit, service improvement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>meetings, teaching</td>
</tr>
<tr>
<td>Tuesday</td>
<td>Pre-clinic patient follow up</td>
<td>Ward based/home assessments (clinic attendees)</td>
</tr>
<tr>
<td>Wednesday</td>
<td>Telephone reviews/admin</td>
<td>MND MDT clinic</td>
</tr>
<tr>
<td>Thursday</td>
<td>Post clinic follow up (referrals etc)</td>
<td>Ward based/home assessments (non clinic attendees)</td>
</tr>
<tr>
<td>Friday</td>
<td>Telephone review/admin.</td>
<td>Weekly meeting with Dr Evans (personal development, patient review, service development)</td>
</tr>
<tr>
<td></td>
<td>Teaching/home assessment (new patients)</td>
<td></td>
</tr>
</tbody>
</table>

Adhoc (not an exhaustive list):

Admin - Dictation, emails, reading and signing dictated letters, maintain and update databases, organise and chair MND MDT meetings, Organise and chair steering group, organise and present teaching/education events, attendance at education events/specialist nurse meetings/conferences, maintaining MND patient information board/information leaflets and ordering of more stock, audit and annual report, attendance at meetings.

Patient – ensuring new patients are seen and appointed to MND clinic, review of case notes, update of patient notes, onward referrals, acting on patient results and liaising with various health care professionals, liaise with and monitor patients attendance at clinic, ensure relevant health care professionals receive relevant patient information, attendance at patient meetings (funding/health etc), maintaining and updating patient information.