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MND Scotland acknowledges the debt it owes to the original contributors to the Champlain Integrated Care Plan on which this Scottish version is modelled. We also acknowledge the work done by the working group of the United Kingdom Royal College of Nurses who developed the document “A Pathway for the Management of Pain in Motor Neurone Disease,” which is now out of print, but has been incorporated and updated within this booklet. We also wish to draw attention to the excellent resources provided by MND Australia at www.mndcare.net.au for both professionals and those living with the condition, which are referenced within this booklet..

A Message to the Primary Carer

When a member of the family is diagnosed with MND, it can be an overwhelming time. It is therefore necessary that a family member, a relative or a friend understands the prognosis of MND and who to contact for advice and support during this time of great distress. It is hoped that this booklet will provide you with a fuller understanding of MND and offer you guidance and support to help with decision making. As soon as a diagnosis is confirmed, families should be put in contact with a member of the MND Scotland Care Team by their Neurologist. The care team is there to identify and source additional support as required for the particular stage of the disease.

The course of MND is variable, so the symptoms experienced and the order in which they appear will vary from individual to individual and not everyone affected will necessarily experience all of the possible symptoms.

You are not alone; although most health care professionals will have little to do after their initial visit early in the disease, they will, however, come to your aid as things change and more input is required – even if they haven’t been in touch for several months. All it takes is a phone call from you advising them of how things have changed.

Taking care of your own health and wellbeing is rarely a primary carer’s priority and, therefore, the carer’s own health is often not given the attention it deserves. However, it is imperative that family carers monitor their own health with the supervision of their GP and think about compassionate leave or a change to working hours if the health of the primary carer is at risk or might become an issue.

Please ensure that this document is made known to the various care professionals who are involved with you and your family so they can order a copy for themselves from MND Scotland.

TABLE OF CONTENTS

	Page
Introduction	1
What is an Integrated Care Pathway?	
Why have an Integrated Care Pathway for MND?	
Who is the Target Audience for the Integrated Care Pathway?	
How should the Integrated Care Pathway be used?	
Key Considerations in MND Disease Management	2
Rate of Disease Progression	
Variable Symptomologies	
Energy Conservation	
Emotional Impact of MND	
Making Best Use of Knowledgeable Professionals	
Energy Conservation Techniques	4
Advance Care Planning and MND	5
Revised ALS Functional Rating Scale (ALSFRS-R)	6
Health Improvement Scotland's Clinical Standards for Neurological Services	7
The Integrated Care Pathways.	11
Mobility Pathway	11
Eating, Drinking and Swallowing Pathway	15
Communication Pathway	18
Respiratory Pathway	20
Cognitive and Behavioural Changes	22
Sexuality	23
Physical Pain	24
Psychological Pain	25
Spiritual Pain	26
Clinical Standards specific to Motor Neurone Disease	31
Appendices	
A, Key Service Resources in Scotland for information and MND Management	33
B, Palliative Care Resources	37
C, Respite Care Services	42
D, MND Books, DVDs and Videos	43

INTRODUCTION

What is an Integrated Care Pathway?

An integrated care pathway (ICP) is a description of a person's anticipated care needs that should be addressed by the multidisciplinary team. It summarises an overview of disease progression under different headings and identifies potential problems that might arise for the client and carer as the illness advances. It also offers a list of resources which should be accessed as required to support clients with MND at different stages of the disease. In most cases access to these specialist services or the suggested resources will require referral from a member of the multidisciplinary team. This anticipatory approach to addressing care needs can benefit clients and families by helping members of the multidisciplinary team identify solutions to potential needs before they arise.

Why have an Integrated Care Pathway for MND?

The goal of an ICP is to promote and support the development of care partnerships and to provide information to empower clients and their carers. Due to the relatively small number of people affected by MND, only a few staff within the NHS or social work departments will have the necessary training and experience to develop a high level of expertise in the management of this disease. This integrated care pathway has been developed to assist carers in understanding the disease process of MND from diagnosis to end of life and to suggest appropriate resources and interventions for different stages of the condition.

Who is the Target Audience for the Integrated Care Pathway?

The ICP is intended to empower both professional and non-professional care providers. Experience of other care plans, for example the Champlain Care Plan developed in Ontario, Canada, on which this ICP draws heavily, has demonstrated, that both people with MND and their families can benefit from an ICP like this. Interest from all parties is welcomed as the ICP is seen as a vehicle to educate and inform everyone involved in the care of a person with MND.

How should the Integrated Care Pathway be used?

The integrated care pathway for MND has been divided into the following areas:

- Mobility
- Eating, Drinking and Swallowing (including oral health)
- Communication
- Respiratory Factors
- Cognitive and Behavioural Changes
- Sexuality.
- Pain

Each of these sections is then presented according to its various stages of progression, based on what the person is still able to do for themselves.

The care plan tables are structured to enable the reader to identify the potential problems or risks which might arise at a particular stage during the course of the disease. It then suggests actions to help manage these problems and resources to help support clients and their carers. A list of suggested resources that are known to us is provided in Appendix A.

While the pathway provides much useful information, *it is not intended to replace professional clinical assessment and support*; neither does it address all possible areas or situations.

Key Considerations in MND Disease Management

MND is a complicated and challenging disease. The following five messages have been identified as crucial considerations for service providers, clients and families dealing with the illness.

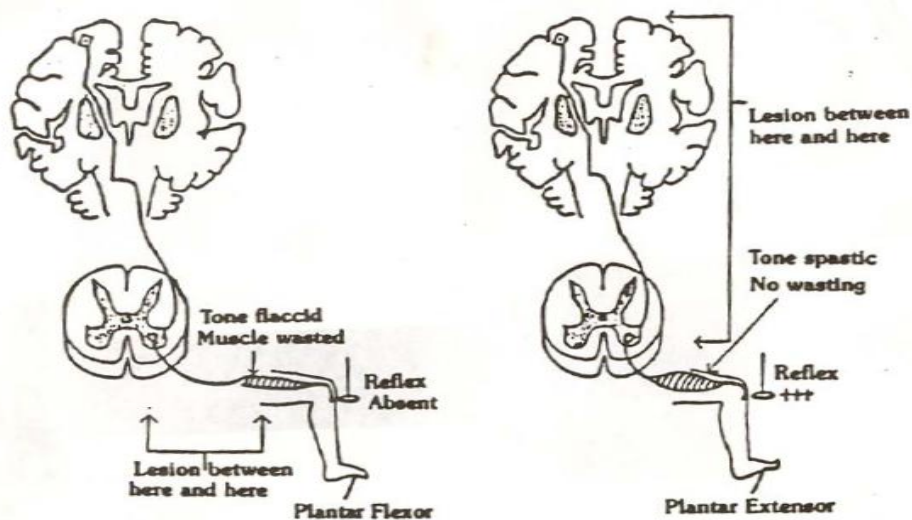
Rate of MND Progression

MND is a degenerative disease. The rate of degeneration of neurones and muscles varies greatly from person to person and is unpredictable. In some cases the disease process moves slowly, and it may even appear that the person has reached a plateau with no apparent change for a long period of time, while in other cases; it can progress steadily at a rapid rate. Some evidence is emerging that the differing rates of progression are related to which biochemical pathways have been damaged in the person with MND. Service providers need to be aware of these differences in disease progression and symptom development and be prepared to manage a wide variety of symptoms and functional changes.

In order to gauge the rate of progression a number of authors have proposed various "functional rating scales" such as Cedarbaum's revised scale (ALSFRS-R) included on page 6 of this booklet. The value of a scale like this is it allows disease progression to be monitored in a reasonably objective way. A disadvantage, as noted by many people, is that a score of "0" does not mean the end of progression, e.g. loss of functional speech is not the same as being unable to vocalise, and inability to walk does not preclude the possibility that a dextrous toe could be used to control some equipment.

Variable Symptomologies

MND destroys motor neurones and can present itself very differently in different individuals. The exact symptoms experienced by someone are related to which areas of the nervous system the disease attacks.



Lower Motor Neuron Lesion

Upper Motor Neuron Lesion

Lower and Upper Motor Neurone Lesions

When the motor neurones of the so-called bulbar region of the brain (cerebellum, medulla and pons) are damaged, speech, swallowing and breathing can all be affected. When the motor neurones of the spinal cord are damaged, one or both arms and/or legs will be affected. In some cases MND can develop to involve all of these areas as well as the trunk.

Energy Conservation

Although the course of MND is unpredictable, fatigue is almost inevitable as a consequence of muscle weakness. Fatigue often leads to complaints of tiredness, diminishing strength, and lack of energy.

Some of the more noticeable signs of fatigue include slower speech and body movements, lower volume and tone of voice, and shortness of breath. Fatigue can be a very disabling symptom, but by recognising the signs of fatigue, knowing what exacerbates these symptoms, and learning strategies to conserve energy for things that are enjoyable, the quality of life for individuals with MND can be improved. See “Session 19 Fatigue and Insomnia” at www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 for strategies to help manage both of these problems.

Emotional Impact of MND

Caring for a loved one with MND is physically challenging, emotionally overwhelming and, despite the welfare state, can be financially stressful. The unpredictable rate of disease progression and impaired communication can have a significant impact on personal relationships. Carers and family members are at increased risk for clinical depression as well as physical illness and injury related to the demands of constant provision of care.

To pre-empt some of the above risks a multidisciplinary care plan should be developed by service providers in conjunction with both clients and their families to ensure a holistic approach in managing the ongoing loss of function and increased isolation associated with this illness. The care plan should take account of how the disease has affected the different areas of the person’s functionality since not all areas will deteriorate at the same rate. An early introduction to palliative care services can help some people to cope.

Making Best Use of Knowledgeable Professionals

Access to healthcare professionals who can work with the client/family unit as a team and are knowledgeable about MND is a very important factor in effectively managing the disease. The members of MND Scotland Care Team are the local experts and serve as an excellent resource to clients, families and service providers. It is important for clients to stay in touch with their family’s GP who should work in conjunction with the MND Care Team Specialist. GPs should provide ongoing follow-up for primary health issues, drug prescriptions and assessment between clinic visits. It is recommended that all individuals affected by MND should contact MND Scotland whose mission is to help people and their families live with the condition and manage side effects of the disease through services such as equipment loan, counselling, welfare & benefits, information and education.

As MND progresses, there are various types of equipment available to assist individuals with mobility, activities of daily living and communication. Choosing the best assistive equipment for their specific situation involves many considerations including an understanding of the rate of disease progression and longer-term needs, as well as issues related to availability of expensive equipment. Particularly in these times of financial constraint it is strongly recommended that clients and families consult with a knowledgeable professional to see what equipment can be loaned or provided from social work or NHS resources to help with their needs. A more complete listing of organisations offering supportive resources can be found in Appendix A.

Energy Conservation Techniques for People with Motor Neurone Disease

Many people living with MND suffer from severe fatigue, which can greatly impact on a person's ability to function independently as well as affecting their quality of life. Occupational therapy may include the use of energy conservation techniques such as restricting the amount of activity, simplifying the way things are done, time management, and/or organisation of your surroundings to minimise effort.

Suggested ways to conserve energy include:

1. Prioritise: Do only the jobs that are most important.
2. Plan ahead: Even out your workload so tasks that require a great amount of energy can be distributed throughout the week.
3. Consider your personal energy budget: Perform the most strenuous activities during the time of day when you have the most energy.
4. Alternate easy and difficult tasks.
5. Pace yourself: Over-exerting yourself can result in greater fatigue.
6. Take frequent rest breaks, at least 10-15 minute every hour
7. Perform activities when seated where possible (e.g.: fold laundry while sitting in a chair or on the couch; do prep work for meals sitting at the kitchen table).
8. Organise your workspace. Avoid reaching, bending, carrying, and climbing.
9. Use labour saving techniques (e.g.: soak dishes before washing).
10. Work with gravity assisting, not resisting..
11. Get plenty of sleep and rest! Plan on 10-12 hours of daily rest (including naps).
12. Use correct body mechanics:
 - a. Keep the head aligned with the trunk and tuck-in the chin.
 - b. Keep the shoulders and hips in alignment.
 - c. Turn your feet. Do not twist your trunk.
 - d. Maintain a pelvic tilt by tucking in the buttocks or keeping one foot raised on a low stool while standing.
 - e. When lifting a low object, bend your knees and lift with your legs. Keep your back straight.
 - f. Push before pulling. Pull before lifting.
 - g. If you must lift or carry, keep objects close to the body.

References:

Pedretti, L. & Early, M. (2001). Occupational Therapy: Practice Skills for Physical Dysfunction. St. Louis, MO: Mosby, Inc.

Trombly, Catherine. (1997). Occupational Therapy for Physical Dysfunction 4th edition. Philadelphia, PA: Lippincott, Williams, & Wilkins.

ADVANCE CARE PLANNING AND MND

A number of different terms are used by people working in this area such as “Advance Care Plan,” “Advance Directive,” “Advance Decision to Refuse Treatment” or “Advance Decision to Refuse Cardiopulmonary Resuscitation.” Some of these terms carry with them legal implications under English Law but, for the moment in Scotland, advance decisions, whatever the term used, have no legal standing although there are guidelines in force from the General Medical Council (GMC) to guide Doctors to good practice in decision making in this area of medicine. For simplicity only three terms will be used in this section, “Advance Care Planning” or “Plan,” “Advance Directive” and “Advance Decision to Refuse CPR.”

Advance Care Planning is considered to be an important part of care, particularly when only palliation can be offered. At its simplest the doctor and the patient should try to “future-gaze” and agree which actions should be taken if certain common or predictable circumstances occur. These decisions should be written down as an advance care plan agreed by the attending doctor and the patient and incorporated into the person’s medical notes in order that all medical staff will then know how the person feels about some common interventions and whether or not they should be applied in his or her case if those precise circumstances arise. For example, for people with advanced MND there is often a high risk of chest infections and some people have been known to refuse antibiotic treatments. Others have been known to refuse the insertion of a feeding tube when it is clear they will soon be unable to swallow. Equally, many people have said they will refuse such interventions when they are only a remote possibility, but have changed their mind as the possibility becomes more likely to be realised. For this reason alone advance care plans should be revisited frequently as circumstances change.

An Advance Directive is another way of formally setting out what care and interventions you would and would not like to have in the event that a medical intervention is required but you have become incapable of indicating your wishes yourself. This could come about, even without the complications of MND, because of unconsciousness or because of what is known as “mental incapacity.”

Advance directives do not necessarily need the involvement of medical staff in their creation, but the existence of an advance directive does need to be made known to medical staff if you expect it to be acted upon. Strictly speaking an advance directive can only be used to say what is unacceptable to you and, by implication, anything you do not mention is therefore acceptable to you, even treatments that have not been invented when you make your advance directive. You cannot use an advance directive to describe what care you do want, with the exception that you can state where you would like to be cared for, if possible.

An Advance Directive to Refuse CPR is a specific kind of advance directive in which you state that it is your wish not to be revived if, for example, your heart should stop beating for some reason. There is now a specific form to be completed and kept with the patient in the case of someone who wishes to create an ADRCPR order.

The ALS Functional Rating Scale — Revised (ALSFRS-R)

After Cederbaum JM *et al* Journal of the Neurological Sciences 169 (1999) 13–21

1. Speech		4. Handwriting	
4	Normal speech processes	4	Normal
3	Detectable speech disturbance	3	Slow or sloppy: all words are legible
2	Intelligible with repeating	2	Not all words are legible
1	Speech combined with non-vocal communication	1	Able to grip pen but unable to write
0	Loss of useful speech	0	Unable to grip pen
2. Salivation		5a. Cutting food and handling utensils (patients without gastrostomy)	
4	Normal	4	Normal
3	Slight but definite excess of saliva in mouth; may have night-time drooling	3	Somewhat slow and clumsy, but no help needed
2	Moderately excessive saliva; may have minimal drooling	2	Can cut most foods, although clumsy and slow; some help needed
1	Marked excess of saliva with some drooling	1	Food must be cut by someone, but can still feed slowly
0	Marked drooling; requires constant tissue or handkerchief	0	Needs to be fed
3. Swallowing		5b. Cutting food and handling utensils (patients with gastrostomy)	
4	Normal eating habits	4	Normal
3	Early eating problems — occasional choking	3	Clumsy but able to perform all manipulations independently
2	Dietary consistency changes	2	Some help needed with closures and fasteners
1	Needs supplemental tube feeding	1	Provides minimal assistance to caregiver
0	NPO (exclusively parenteral or enteral feeding)	0	Unable to perform any aspect of task
6. Dressing and hygiene		7. Turning in bed and adjusting bed clothes	
4	Normal function	4	Normal
3	Independent and complete self-care with effort or decreased efficiency	3	Somewhat slow and clumsy, but no help needed
2	Intermittent assistance or substitute methods	2	Can turn alone or adjust sheets, but with great difficulty
1	Needs attendant for self-care	1	Can initiate, but not turn or adjust sheets alone
0	Total dependence	0	Helpless
8. Walking		9. Climbing stairs	
4	Normal	4	Normal
3	Early ambulation difficulties	3	Slow
2	Walks with assistance	2	Mild unsteadiness or fatigue
1	Nonambulatory functional movement	1	Needs assistance
0	No purposeful leg movement	0	Cannot do
10. Dyspnoea		11. Orthopnoea	
4	None	4	None
3	Occurs when walking	3	Some difficulty sleeping at night due to shortness of breath, does not routinely use more than two pillows
2	Occurs with one or more of the following: eating, bathing, dressing (ADL)	2	Needs extra pillows in order to sleep (more than two)
1	Occurs at rest, difficulty breathing when either sitting or lying	1	Can only sleep sitting up
0	Significant difficulty, considering using mechanical respiratory support	0	Unable to sleep
12. Respiratory insufficiency			
4	None		
3	Intermittent use of BiPAP		
2	Continuous use of BiPAP during the night		
1	Continuous use of BiPAP during the night and day		
0	Invasive mechanical ventilation by intubation or tracheostomy		

Clinical Standards for Neurological Services

NHS Quality Improvement Scotland (now called Health Improvement Scotland) set up a steering group in 2005 to review and scope the provision of neurological health services in the context of the strategic direction set out by the Scottish Government in Partnership for Care: Scotland's health white paper 2003. The group reported in April 2006, and identified the need to undertake a stocktaking exercise to establish the nature and quantity of existing neurological service provision. The review found that services available to those with neurological conditions in Scotland vary significantly between NHS Boards.

Specific findings of the report included:

- services for people with neurological conditions varied across Scotland
- NHS Boards were unable to describe their neurological health services accurately
- NHS Boards appeared to consider neurological health services a low priority
- NHS Boards were experiencing recruitment difficulties to deliver neurological health services
- there were no waiting times targets for follow-up appointments
- there was a lack of communication among service providers for people with neurological conditions
- availability of inpatient beds was limited, particularly in services such as rehabilitation, palliative and respite care
- specialist nurses were considered a valuable resource, but their provision varied greatly across the NHS Boards, and
- the recent pilot of telemedicine neurological services in the north of Scotland was regarded as successful by patients, consultants and nurses.

Standard 1: General neurological health services provision

An effective and comprehensive neurological health service is available and offered across all NHS Boards.

Rationale

Individuals should have access to all aspects of neurological care regardless of where they live.

Patient care is enhanced by the provision of up-to-date and accurate written and verbal information.

The steering group also recommended the development of generic clinical standards for the provision of services for those affected by neurological conditions, to be based on the principles in the Department of Health's National Service framework (NSF) for long-term conditions.

The standards are applicable to all NHS territorial Boards as well as the National Waiting Times Centre. The standards apply to any care setting within an NHS Board including primary, secondary and tertiary care.

Vision for neurological health services in Scotland

It is intended that every patient in Scotland referred with a disorder of the nervous system should experience a quality of care that gives confidence to patient, referrer and provider. This will be achieved by ensuring that the individual:

- is assessed by the right person at the right time
- has timely access to investigations that promote care
- is encouraged to participate in decision-making on a partnership basis when desired, and
- has easy access to information and services that enhance the long-term management of their condition.

In October 2009 the Clinical Standards for Neurological Services were finally published; of the nineteen published standards the first four are generic and apply to all neurological health services while three, standards 11, 12 and 13, apply to people affected by MND. These seven standards, which set out the minimum acceptable levels of service relevant to people affected by MND, are reproduced on the following pages.

Consistent and ongoing data collection allows NHS Boards to monitor and review their services on an ongoing basis, for the purpose of service improvement. Success will not occur without clinician and management engagement, the active participation of NHS Board IT departments and a long-term approach to system development.

The Neurological Services Data and Audit Group will identify and agree a common dataset for neurological services to ensure consistency across all NHS Boards.

Essential criteria

- 1.1 The NHS board makes accurate and current information available about its existing designated services for patients with neurological conditions.
- 1.2 The NHS board has a minimum 3-year plan for the provision of neurological health services to its population. This plan is published and subject to annual review.
- 1.3 The NHS board works collaboratively with the Neurological Alliance of Scotland, other patient support groups and charities to ensure that patients and their carers are made aware of the resources available nationally and

locally through voluntary sector partners.

- 1.4 The NHS board provides accurate and current information to patients and their carers about their condition.
- 1.5 The NHS board provides resources to ensure collection and analysis of data in relation to neurological services activity and outcomes, as identified by the Neurological Services Data and Audit Group.
- 1.6 The data collected within the common dataset is used to improve patient care.

Standard 2: Access to neurological health services

Standard statement 2

Patients with suspected neurological conditions are assessed by clinicians who specialise in neurological conditions. Patients are assessed within timescales dictated by their clinical needs.

Rationale

Evidence suggests that neurological conditions are most effectively dealt with by specialist clinicians. Timely access to neurological health services is important in order to achieve good outcomes for patients with some neurological conditions. The Scottish Government Health Directorates has established overall maximum waiting times targets, but some patients will need to be seen within shorter timescales. Providing clear and efficient referral systems will enhance NHS Boards' ability to achieve targets.

Access to neurological health services for patients in remote or rural areas is improved by access to telemedicine.

Essential criteria

- 2.1 The NHS board demonstrates that a minimum of 90% of outpatient demand for all neurological health services can be met by substantive resources without resorting to waiting times initiatives, reliance on temporary staffing or other short-term measures.

- 2.2 Outpatients are referred and triaged electronically. They are allocated to the appropriate waiting list within 5 working days of receipt of the referral at the centre in at least 95% of cases.

2.3a The NHS board ensures that the neurology service has a communication process for discussion of urgent cases with a neurologist at all times.

2.3b Where the neurologist identifies an outpatient referral as urgent, the patient is seen within 10 working days of triage in at least 90% of referrals.

2.4 Initial advice following an urgent request for a neurological opinion for inpatients in non-neurological settings occurs within 24 hours.

2.5 At least 80% of patients with a neurological condition requiring transfer are admitted under the care of a neurologist within 48 hours of acceptance.

2.6 Individuals affected by chronic neurological disease are provided with a contact point within the relevant neurology service to allow for re-entry into the service.

2.7 District general hospitals and regional neurology centres have on-site 24-hour access to telemedicine facilities.

Standard 3: Patient encounters in neurological health services

Standard statement 3

Neurological health services provide a high quality of care that meets the needs of patients, referrers and providers

Rationale

The ability to meet a patient's needs is fundamentally dependent on the quality of the consultation. Other factors such as a good physical environment, timeliness and provision of information are important to enhance the interaction between patient and clinician. rapid, accurate, legible and accessible communication between all those involved with the patient is also of paramount importance.

Essential criteria

- | | | | |
|------|---|------|--|
| 3.1 | The professional development and maintenance of standards of all staff working within neurological health services is monitored by the NHS board. | 3.5 | Patients are provided with practical information in advance of their first appointment specific to the appointment and department. |
| 3.2a | The NHS board implements systems to collect patient feedback to improve the neurological health services on an ongoing basis. | 3.6a | The outpatient service is conducted in a safe and comfortable environment for patients and is surveyed annually to ensure the quality is maintained. |
| 3.2b | The NHS board implements systems to collect feedback from clinicians referring into the service to improve the neurological health services on an ongoing basis. | 3.6b | Designated private facilities are available on wards for discussions between staff, patients, family and carers. |
| 3.2c | The NHS board implements systems to collect neurological service staff feedback on its neurological health services on an ongoing basis. | 3.7a | New patient encounters are scheduled to allow a minimum of 30 minutes consultation time with a clinician and 30-40 minutes with trainees. |
| 3.2d | The NHS board acts on the patient, referrer, and staff feedback it collects. | 3.7b | Return patient encounters are scheduled to allow a minimum of 15 minutes consultation time with a clinician and 15-20 minutes with trainees. |
| 3.3 | The NHS board provides access to, and demonstrates participation in, communication training for all staff having direct contact with patients with neurological conditions. | 3.7c | Clinicians have a facility to schedule additional time where a prolonged consultation is anticipated. |
| 3.4 | Patient waiting times in clinics are monitored and patients receive an | 3.8 | A minimum of 90% of outpatient letters are electronically dispatched within 5 working days of the consultation. |
| | | 3.9a | All inpatients are discharged with a printed immediate discharge summary. |
| | | 3.9b | Immediate discharge information is sent to the GP electronically in at least 90% of cases. |
| | | 3.9c | Final discharge summaries are dispatched electronically to the GP within 5 working days of discharge in at least 95% of cases. |

Standard 4: Management processes in neurological health services

Standard statement 4

Neurological health services have an effective patient management process from the point of first referral.

Rationale

Patients with neurological conditions benefit from the ready availability of a variety of different specialist investigation and management resources. In some cases, complex needs demand access to a wide range of services, including rehabilitation, self-management options and palliative care. A common rate-limiting step in the delivery of care of the acutely ill patient is the ability to access the acute neurology inpatient unit and its associated resources.

One third of all patients attending neurology outpatient departments have neurological symptoms unexplained by disease, but who may benefit from specialist management. In addition, patients with neurological conditions are much more likely to have psychiatric disorders than the general population. Failure to recognise and treat such co-morbid disorders is common and may seriously undermine the patient's neurological management and worsen their prognosis.

Access to clinical neuropsychology is important for the diagnosis of disorders of cognition, the management of patients with neurologically unexplained symptoms and psychological support for patients with other neurological conditions.

Community health partnerships (CHPs), or equivalent, have a role in integrating primary care and specialist services with social care. This role will support services to provide consistent care throughout a patient's journey and discharge from neurological health services.

Essential criteria

4.1 At every consultation, all patients are offered a copy of the GP's letter or a management plan. Any changes to medication are provided in writing immediately to the patient.

4.2a All neuro-imaging procedures are reported by a neuroradiologist, or a general radiologist who has had specialist neuroradiological training.

4.2b All neurophysiology procedures are performed and reported by a neurophysiologist, or medically trained staff with neurophysiological training.

4.3 At the conclusion of the care episode, 80% of patients are transferred back from the neurological unit to the referring unit within 2 working days of transfer request.

4.4a The neurology service has access to an integrated neuropsychology and neuropsychiatry service providing a diagnostic and treatment service for patients with neurological symptoms unexplained by disease, and patients with defined neurological disease that have co-morbid psychiatric disorders.

4.4b At least 80% of patients referred to this service requiring urgent assessment will have initial contact within 24 hours if referred from inpatient consultation, or within 20 working days if referred from outpatient consultation.

4.5 The neurology service has access to specialist neuropsychological assessments and rehabilitation contributing to the diagnosis and management of neurological conditions.

4.6 The NHS board provides designated rehabilitation services specifically for people with neurological symptoms.

4.7 There are multidisciplinary systems in place, with input from a specialist clinical pharmacist for:

- safe use of medicines
- access to formulary medicines
- use of non formulary and unlicensed medicines
- education of non medical and medical prescribers, and
- regular medicines reconciliation and review.

4.8 The neurology service has channels of communication with the individual responsible for long term conditions in the local community health partnerships, or equivalent, to co-ordinate the provision of services, equipment and medication, by the NHS and social services.

MND Scotland Integrated Care Pathway – Mobility

Presentation			Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Energy Level	Activities of Daily Living	Mobility				
Stage 1: Mild Motor Symptoms						
Still active but tires more easily due to loss of motor neurones	Able to manage with normal life and daily routines	May have some limitations in sports or other physical activities	<p>Challenges associated with informing family, colleagues and friends about MND diagnosis</p> <p>Changes to speech and walking due to the MND are often misinterpreted by others</p> <p>Answering children's questions with age-appropriate information is recommended as they are perceptive and will be aware something is 'not quite right' in the family</p> <p>Risk of depression due to reduced energy.</p>	<p>Reduced energy affecting quality of life.</p> <p>Frustration with limited abilities leading to rash decisions.</p>	<p>Education on the roles of physiotherapist (PT) and occupational therapist (OT).</p> <p>Education on the partnership between the NHS, Social Work and MND Scotland's equipment loan service for equipment supply.</p> <p>Introduction to energy management (see p5).</p> <p>Education regarding exercise guidelines (do's and don'ts).</p>	<p>MND Clinic, GP, Physiotherapist (PT), Occupational Therapist (OT), District Nurse (DN) and Social Worker (SW).</p> <p>MND Scotland Care Team and Welfare Rights & Benefits Service to ensure access to entitlements. MND Scotland Counselling service.</p> <p>Internet resources: www.mndscotland.org.uk/information/factsheets e.g. Factsheets 5A to 5D</p> <p>www.mndcare.net.au/living-with-mnd See also the link from the above web page to "MND Aware Session 5 The needs of people living with MND – an overview"</p>
Stage 2: Moderate Motor Symptoms						
Fatigue related to increased effort for certain activities	Still independent but requires more time and energy to complete activities	Still independent, but with more difficulty walking and getting up/down from lower surfaces (e.g. toilet, sofa) due to reduced balance and/or leg/foot weakness	<p>Reduced social activities</p> <p>Reduced intimacy with sexual partners due to fatigue and anxiety</p> <p>Financial concerns regarding costs of "extras" to meet the needs of the condition. Concerns about future employment of both the person and possibly their carer.</p> <p>Embarrassment and self-image issues associated with need for assistive devices</p> <p>Early introduction to palliative care services for support, information and education is beneficial to some people with MND (pwMND) and their families.</p>	<p>Limited energy for activities</p> <p>Injury from falls</p> <p>Pain due to joint stiffness and cramps</p> <p>Potential physical challenges within the person's home environment</p>	<p>Introduction to assistive devices for upper and/or lower body activities (e.g. built up pen, cutlery, plate-guards)</p> <p>Equipment to assist with mobility; walking stick(s), wheeled walker, foot brace (ankle-foot orthoses or AFO), raised toilet seat, riser-recliner chair</p> <p>Review home to determine adaptability, consider wet room, grab-rails and handrails</p> <p>Referral to community agencies to assist with living at home</p> <p>Application for Blue Badge</p> <p>Active range of motion (ROM) exercises. Self stretching exercises to maintain flexibility and control cramps</p> <p>Medication for cramping and stiffness</p>	<p>As Above plus:</p> <p>Consideration of needs assessments for assistive equipment & devices and home adaptations (advice available from OT/PT/SW/MNDS Care team)</p> <p>MND Scotland – equipment loan service</p> <p>Local Authority Blue Badge Scheme (MNDS Welfare and Benefits Officer can apply, if mandated)</p> <p>See page 5 "Energy Conservation"</p> <p>www.mndscotland.org.uk/information/factsheets</p> <p>Home Care Services from local Council, Care Groups and private sector services, e.g. home help, befriending, Crossroads Care etc.</p> <p>Internet Resources: www.irrd.ca/education Ambulatory aids: a basic guide www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware Session 15 Movement and Joints</p>

MND Scotland Integrated Care Pathway – Mobility

Presentation			Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Energy Level	Activities of Daily Living	Mobility				
Stage 3: Advanced Motor Symptoms						
<p>Most activities are tiring, requiring frequent rest breaks.</p> <p>May nap daily</p> <p>Muscle wasting and weight loss</p> <p>May have a Blue Badge parking permit</p>	<p>Requires caregiver assistance for some ADLs</p> <p>Increased use of assistive devices to compensate for loss of ability (shower stool, grab bar in bathroom, raised toilet seat, built up utensils)</p>	<p>Walking using furniture, sticks or wheeled walker in the home</p> <p>Using a wheeled walker or chair for outings</p> <p>Able to transfer independently from raised surfaces (e.g. raised toilet seat) or needs one-person assistance from normal or lower height surfaces (e.g. car seat, sofa)</p> <p>May have difficulty supporting trunk and neck when sitting and/or walking</p> <p>May need assistance to manoeuvre into and out of bed.</p>	<p>Limited social outings</p> <p>Client may consider taking one last family holiday before safety issues related to travelling and insurance become a concern</p> <p>Reduced intimacy with sexual partners due to joint pain, stiffness and fatigue.</p> <p>Ongoing loss as pWMND faces greater challenges in expressing themselves physically in intimate relationships.</p> <p>Increased demand on family members to participate in personal care of the individual</p> <p>Family may consider moving to accommodate the pWMND's (and caregiver's) current and future physical limitations. However, this consideration should be tempered by the fact that moving house might also take the family away from good neighbours and an established support network.</p>	<p>Same risks identified above, plus:</p> <p>Pain due to poor positioning or lack of support for head or arms due to muscle loss</p> <p>Client injury due to overexertion, falls, or unsafe assistance technique used by caregiver</p> <p>Caregiver injury from fatigue or unsafe pWMND assistance technique</p> <p>Reduced ability to do household tasks (e.g. laundry, meal preparation)</p> <p>Limited access to places with stairs</p>	<p>Continued education re: energy management</p> <p>Education on proper positioning and support for comfort (sitting and lying)</p> <p>Client and Carer education re: safe techniques to assist the person (e.g. body mechanics, transfer techniques and equipment)</p> <p>Equipment loan for self care, transfers and mobility (built up utensils, transfer board or disc, commode, motorised bed, walker, AFO(s), manual/power wheelchair, special car-seat)</p> <p>Home modifications for accessibility e.g. 2nd hand rail for stairs, handrails for bath, stair-lift, wheelchair ramps, creation of wet room.</p> <p>Referral for at-home assistance (e.g. social work home-care services)</p> <p>Recommendation for attendant care, e.g. "Crossroads" or similar for respite.</p> <p>Continue with self ROM and stretching exercises; refer to physiotherapist for assistance as required</p> <p>Education re: funding for equipment and services</p> <p>Education re: potential safety risks when driving Refer for driving assessment and/or vehicle adaptation</p>	<p>OT, PT, DN, MNDS Care Team, and SW</p> <p>MND Scotland equipment loan service</p> <p>Home Care Services from local Council, Care Groups and private sector services, e.g. home help, befriending, Crossroads Care etc</p> <p>Review benefits entitlements if DLA was not awarded or was awarded at lower rate for either care or mobility. MNDS Welfare & Benefits Service.</p> <p>Refer to community palliative care physician and hospice support program</p> <p>Building adaptations and accessibility funding through Social Work</p> <p>Internet Resources: The Rehabilitation Centre On-Line Education www.irrd.ca/education Assisted ROM exercises for arms and legs to maintain joint flexibility Principles of transfers for Health Care workers</p> <p>See also internet sites recommended in stage 2</p> <p>Resource Material: www.mndscotland.org.uk/information/factsheets</p> <p>MND Scotland factsheet 17 Motoring and MND.</p> <p>Driving Assessment Program (available through Astley Ainslie Hospital, see p32.)</p>

MND Scotland Integrated Care Pathway – Mobility

Presentation			Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Energy Level	Activities of Daily Living	Mobility				
Stage 4: Severe Motor Symptoms						
<p>Limited physical and social activities due to fatigue</p> <p>Regular rest breaks/naps taken one or more times daily</p> <p>Continued muscle wasting and weight loss</p>	<p>Assistance required for all ADLs with pWMND participating as able</p> <p>No longer driving</p>	<p>Using a combination of wheeled walker and manual/power wheelchair for mobility needs (dependent on energy level)</p> <p>Using motorised bed</p> <p>May have difficulty supporting trunk and neck when sitting and/or walking</p> <p>Transfers with caregiver assistance and equipment (transfer disc, belt and/or board)</p>	<p>Introduction of motorised (hospital) bed increases loss of intimacy (unable to sleep with a partner) and increases labelling as “disabled”</p> <p>Lack of privacy in the home due to increased presence of health care providers and equipment</p> <p>Increased social isolation</p> <p>Decreased self-esteem and self image</p> <p>Potential for caregiver burnout (need to consider respite needs of the family)</p>	<p>Same risks identified in Stage 2, plus:</p> <p>Limited endurance for sitting/standing and for walking, due to poor neck and trunk muscle weakness</p> <p>Carer fatigue or burnout</p> <p>Social isolation due to complex care needs</p> <p>Bedsore due to lack of mobility and need for help to reposition.</p> <p>Muscle cramps and oedema due to lack of muscle movement causing poor circulation</p>	<p>Continued education re: safety and energy management</p> <p>Education on proper positioning and support for limbs and head; may include prescription of a neck collar</p> <p>Equipment assessment and update including:</p> <ul style="list-style-type: none"> • wheelchair seating (cushion, tilt, headrest, laptray) for positioning and comfort. • mattress (pressure relief/air flow) <p>In-home modifications for wheelchair accessibility (porch lift, moving bed to ground floor, installation of wetroom, ramps, personal hoist, etc.)</p> <p>Assisted ROM exercises and stretches</p> <p>Airflow mattress/reposition in chair/bed to relieve pressure</p> <p>Regular skin inspection</p> <p>Increased hours of in-home assistance, consider introduction of palliative nursing.</p> <p>GP/DN should liaise with MND Scotland Care Team member.</p>	<p>OT, PT (in collaboration)</p> <p>MND Scotland equipment loan service and Welfare Rights & Benefits Service to ensure access to any increased entitlements</p> <p>Respite care services and hospice programs</p> <p>Family Support Groups (Hospice, and MND Scotland)</p> <p>Palliative care input by GP, DN, Hospice services</p> <p>Wheelchair services</p>
Stage 5: Loss of Most Motor Control						
<p>Very little energy</p> <p>Significant weight loss and muscle wasting</p> <p>Spends most of the time in riser recliner armchair or in bed</p>	<p>Completely assisted by caregivers</p>	<p>Dependent on caregivers for bed mobility</p> <p>Wheelchair dependent (special seating required)</p> <p>Transfers using mechanical hoist</p>	<p>Client and family are experiencing issues related to anticipatory grief and sense of loss</p> <p>Client and family may need assistance to plan for celebration of life or funeral arrangements</p> <p>Increased financial demands on the family due to progression.</p>	<p>Same as Stage 4</p>	<p>Continued education re: safety (patient and caregiver), positioning and energy management</p> <p>Equipment assessment and update, as required</p> <p>Assisted ROM exercises and stretches</p> <p>Increased need for emotional support</p> <p>Review need for referral to palliative care services (if not already done)</p>	<p>Social Worker, OT, PT consult as required</p> <p>Palliative care physician</p> <p>Respite and hospice programs</p> <p>Spiritual support if religious.</p> <p>MNDS Counselling Service</p> <p>Family Support Groups (Hospice support and MND Scotland)</p>

MND Scotland Integrated Care Pathway – Mobility

Presentation			Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Energy Level	Activities of Daily Living	Mobility				
Stage 6 Late stage of illness						
Extreme fatigue Varying levels of consciousness Increased pain/discomfort	Complete assistance	Bedridden	Physical contact with the pWMND is very important, e.g. holding hands. Some family members may need to be encouraged to continue to physically connect with the pWMND through avenues such as touching, massage or hugging	Same as Stage 4 and 5	Continued education on safety, positioning and energy management Assisted ROM exercises and stretches Increased involvement of visiting nursing staff Increased involvement of in-home hospice volunteers Assessment of spiritual needs and connecting to spiritual resources Review need for referral to palliative care services (if not already done)	GP, DN, SW staff Respite and hospice programs Spiritual resources MND Scotland Care Team and also for Counselling, Welfare & Benefits and Equipment Loan.
Stage 7 End of Life						
Level of consciousness decreasing Medications to manage pre-death symptoms	Complete assistance	No transfers Client is bedridden		Increased agitation Difficulty breathing Muscle and joint pain, cramps and oedema from immobility	Palliative care pain and symptom management	GP, DN, SW, MND S Care Team Respite and hospice programs Spiritual resources Palliative care physician/hospice staff

MND Scotland Integrated Care Pathway – Eating, Drinking and Swallowing

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage Anytime				
Decreased Intake of Food/Fluids	<p>Advance Directives/Care Plans need to be discussed with family and palliative care doctor.</p> <p>Families may be concerned that the pWMND will suffer if they do not have enough food. Education is required around changes in appetite, desire for food, and changes in the body's ability to use nutrients. Carers should be helped in recognising when feeding has become more harmful than beneficial</p>	<p>Malnutrition or dehydration due to:</p> <p>Decreased appetite due to fatigue and/or depression</p> <p>Problems chewing &/or swallowing food & liquid due to dysphagia, weak lip seal, nasal regurgitation, or presence of thick mucus</p> <p>Decreased pulmonary function resulting in challenges to coordination of eating and breathing.</p> <p>Fatigue due to increased time and energy to prepare food and to eat a meal</p> <p>Choking due to dysphagia and decreased respiratory function</p> <p>Decreased quantity of food consumed due to decreased appetite, dysphagia and decreased activity</p> <p>Decreased arm function resulting in decreased ability to prepare meals and decreased ability to self-feed</p> <p>Decreased quality of intake due to avoidance of problem foods</p>	<p>Improve visual presentation of food Introduce energy rich small meals and snacks. Ensure social interaction at mealtime</p> <p>Use proteases to break down mucus. Use suction to remove mucus. Modify food texture or liquid consistency. Educate re: safe swallowing strategies</p> <p>Small, energy rich, frequent meals, Energy conservation strategies</p> <p>Consider gastrostomy to support energy and fluid intake.</p> <p>Training in Heimlich Manoeuvre and emergency response for carers.</p> <p>Maintenance of consistent food temperature using double-walled bowls filled with hot water.</p> <p>Provide assistance in meal preparation Introduce adapted tools for eating and drinking</p> <p>Nutritional supplements – milkshakes, smoothies, commercial supplements, thickeners</p>	<p>Hospital Consultant Dietician, SLT, GP and DN</p> <p>MND Scotland Care Team</p> <p>Internet Resources: www.mndscotland.org.uk/information/factsheets MND Scotland Factsheets, 8 Care Planning and end of life Issues 24, Powers of Attorney 44 Advance Directives</p> <p>www.mndcare.net.au/living-with-mnd www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Session 11 Swallowing and Nutrition</p>
Decreased intake of fluids	<p>Advance directives should be discussed with family and palliative care doctor</p>	<p>Dehydration due to difficulty swallowing fluids (dysphagia and poor lip seal)</p> <p>Decreased independence while toileting might cause a decrease in fluid intake (due to toileting issues). Inability to push with abdominal muscles might lead to inability to void bowels or bladder.</p> <p>Psychological changes due to dehydration.</p>	<p>Introduce fortified drinks, thickened fluids and alternative fluid sources in the diet e.g. soups fruit sauces/ smoothies</p> <p>Assistance in toileting alternative equipment, e.g. urinal, condom catheter, Foley catheter, protective clothing</p>	<p>Dietician, GP and DN, OT for adaptations to toilet. MND Scotland Care Team</p>
Elimination		<p>As above, also:- Constipation due to:- decreased activity level decreased fibre intake decreased fluid level medications (e.g. amitryptiline, codeine)</p>	<p>Include high fibre foods in the diet (e.g.. whole grain breads and cereals, vegetables, fruit), increase fluid intake, modify medications, stool softeners, motility agents, laxatives</p>	<p>Dietician GP and DN MND Scotland Care Team</p>

MND Scotland Integrated Care Pathway – Eating, Drinking and Swallowing

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 1 Mild Eating or Swallowing Difficulties				
<p>Complains of chewing or swallowing difficulties with some solid foods or runny liquids.</p> <p>Occasional choking fits Prolonged mealtimes Increased fatigue during mealtimes.</p> <p>Slight weight loss indicated by loose clothing.</p>	<p>Client may feel socially embarrassed in restaurants or when with guests resulting in increased social isolation.</p> <p>Client may be embarrassed if food has to be cut for them due to arm weakness. Increased expectation of caregiver to prepare special meals to adapt texture.</p> <p>Aversion to eating/drinking to avoid choking.</p>	<p>Aspiration/ Choking</p> <p>Decreased intake of both food and fluids, insufficient energy intake – malnutrition and dehydration.</p> <p>Psychological changes due to dehydration/ hypoglycaemia.</p>	<p>Avoidance of foods that are difficult to chew and swallow (e.g., tough meat raw vegetables). Introduction of safe swallowing strategies</p> <p>Small frequent energy rich meals</p> <p>Client education on effective coughing technique</p> <p>Remain focused during eating Continue to maintain good oral hygiene practices including visiting the dentist</p>	<p>Dietician, GP, DN and, SLT</p> <p>MND Scotland Care Team</p> <p>MND Scotland factsheets: www.mndscotland.org.uk/information/factsheets 6 Feeding Tubes 34 Adapting to Swallowing Problems</p> <p>www.mndcare.net.au/living-with-mnd</p> <p>www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware</p> <p>http://www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Sessions 11 Swallowing and Nutrition, 12 Saliva and Mouth Care & 13 Gastrostomy (PEG & RIG).</p>
Stage 2: Diet Texture Modifications Required				
<p>Difficulty managing food and/or liquids.</p> <p>Progressive weight loss.</p> <p>Possibly decreased respiratory function contributing to choking and aspiration concerns.</p>	<p>Loss of pleasure of eating food as well as loss of enjoyment of socialisation related to shared meals with friends and family.</p> <p>Choking episodes are very upsetting to family members and friends.</p> <p>Some carers experience feelings of 'guilt' that they can still enjoy food and may choose to not eat in front of their family member or choose a bland diet more similar to what the individual with MND is eating.</p> <p>Ongoing risk of social isolation due to inability to eat or drink in public.</p> <p>Ongoing burden for caregiver to prepare and supervise meals.</p> <p>Early introduction to palliative care services for support, information and education is beneficial to some pWMND and their families</p>	<p>Choking and aspiration due to dysphagia and increased presence of saliva.</p> <p>Loss of sense of enjoyment typically associated with eating. Malnutrition</p> <p>Dehydration due to inadequate liquid intake leading to possible psychological changes.</p> <p>Decreased oral hygiene due to difficulty swallowing and fatigue.</p>	<p>Swallowing assessment by SLT.</p> <p>Client education on effective coughing techniques.</p> <p>Family and caregiver education on assisted coughing technique.</p> <p>Education of family and caregivers re: first aid for choking.</p> <p>Modify texture of diet.</p> <p>Discuss options re: feeding tube (Percutaneous Endoscopic Gastrostomy - PEG tube) – pWMND is more able to tolerate surgery at an early stage of the disease.</p> <p>Consider using electric toothbrush and flossing aids</p>	<p>SLT, Dietician, GP, PT and DN MND Scotland Care Team</p> <p>MND Scotland factsheets: www.mndscotland.org.uk/information/factsheets 6 Feeding Tubes 34 Adapting to Swallowing Problems</p>

MND Scotland Integrated Care Pathway – Eating, Drinking and Swallowing

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 3: Moderate Difficulty with Eating/ Swallowing				
<p>Increased frequency of choking and aspiration.</p> <p>Increased difficulty eating and breathing simultaneously.</p> <p>More pronounced weight loss.</p>	<p>Clients need emotional support for reactions associated with gastrostomy, including change in body image</p> <p>If pWMND has a gastrostomy during early stages they may be able to continue to eat/drink normally. This may assist with acceptance of the gastrostomy</p> <p>Carers may be uncomfortable with cleaning and managing the feeding tube and have to make an effort to overcome their reactions</p> <p>Family and caregivers need to be aware of risk of pneumonia and discuss patient's treatment decisions as part of advance directive/care plan in the event of an infection.</p> <p>Client and family may need assistance to plan for celebration of life or funeral arrangements</p>	<p>Choking and aspiration due to dysphagia, fatigue and excess saliva</p> <p>Aspiration pneumonia (risk increases with repeat episodes)</p> <p>Silent aspiration i.e. when foreign material enters the trachea or lungs with no noticeable signs to the pWMND (or carer)</p> <p>Halitosis</p> <p>Oral thrush</p> <p>Gingivitis and tooth decay</p>	<p>Insertion of feeding tube if this has been decided by pWMND (e.g. PEG tube – Percutaneous Endoscopic Gastrostomy)</p> <p>Support pWMND's preferred method for receiving nutrition (tube feeding and/or oral feeding)</p> <p>Adherence to modified texture diet for oral feeding</p> <p>Use of mouth washes to assist with mouth care.</p> <p>Drug treatments or suctioning may be necessary to manage excess saliva and/or mucus.</p> <p>Increase liquid intake and use a nebuliser to assist with dry mouth.</p> <p>Rinse mouth with Bicarbonate of soda solution (½ teaspoon per tumbler of water) to ease tingling caused by thrush.</p> <p>Discuss medication management of excess saliva with a health care professional</p> <p>Client should have access to a physician with palliative care expertise who is able to do home visits</p>	<p>Dietician, DN, SLT, GP</p> <p>MND Scotland Care Team</p> <p>www.mndscotland.org.uk/information/factsheets MND Scotland factsheets: 34 Adapting to Swallowing Problems</p> <p>www.irrd.ca/education Therapy/Treatment - Swallowing Disorders</p>
Stage 4: Severe difficulty with Oral Feeding				
<p>Severe dysphagia.</p> <p>Decreased respiratory function (necessary to support eating)</p>	<p>Travel and visits outside the home are severely restricted unless all feeding equipment can be transported.</p> <p>Transportation of equipment increases stress on caregiver for simple outings over extended hours</p> <p>If caregiver goes out alone, substitute care must be found to help around PEG feeding (respite)</p>	<p>Airway obstruction/ aspiration (all ingestion by mouth is unsafe – however, pWMND may choose to continue with oral feeding regardless of the risk involved)</p>	<p>If pWMND has a feeding tube: Tube feedings as tolerated to maintain hydration and basic nutritional needs</p> <p>If pWMND does not have a feeding tube: Continue to assist pWMND with oral feeding as tolerated.</p>	<p>MND Scotland Care Team</p> <p>Dietician, DN, SLT & GP</p>

MND Scotland Integrated Care Pathway – Communication

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 1: Mild Speech Disturbances				
<p>Mild speech changes with some detectable speech disturbance particularly during times of stress and fatigue. These may include:</p> <ul style="list-style-type: none"> • Some difficulty with articulation and pronunciation (e.g. slurring due to weakness in lips and tongue muscles) • Voice hoarseness/strained voice quality • Reduced volume • Tongue weakness (may be accompanied by fasciculation or muscle twitching) • Nasality of speech with weakening of the soft palate muscles <p>Speech remains understandable, but rate, articulation, loudness and resonance may be impaired</p>	<p>Anxiety and fear due to anticipated communication challenges associated with MND disease process</p> <p>Fear of job loss and loss of self-esteem associated with employment</p> <p>Embarrassment due to changes associated with impaired speech</p> <p>Challenges associated with informing family, colleagues and friends about MND diagnosis</p> <p>It is important to inform colleagues about neurological changes that are occurring as they may be misinterpreted (e.g. slurred speech might be taken for alcohol misuse) Children will need to be informed as they are perceptive and will be aware something is 'not quite right' in the family</p>	<p>Increased difficulty with speech as the day goes on (fatigue).</p> <p>Social embarrassment causing reduced participation in conversations.</p>	<p>Provide pWMND with the opportunity to ask questions</p> <p>Provide education re: energy conservation</p> <p>Provide education regarding compensation strategies to:</p> <ul style="list-style-type: none"> • minimise environmental adversity (i.e. communicate in a quiet, well lit area, face to face, for capacity to read lips) • establish context of message. <p>Use of amplification devices to compensate for lack of volume.</p>	<p>SLT,</p> <p>MND Scotland Care Team</p> <p>Internet Resource Materials: www.mndscotland.org.uk/information/factsheets</p> <p>MND Scotland Factsheet 30 Communication Strategies</p> <p>www.mndcare.net.au/living-with-mnd</p> <p>www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware</p> <p>www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Session 14 Communication</p>
Stage 2: Mild to Moderate Speech Changes				
<p>Mild to moderate dysarthria (difficulty speaking)</p> <p>Increased severity of all symptoms (may include slurring, hoarseness, reduced vocal intensity, nasality)</p> <p>Communication becomes more challenging due to increasing fatigue and weakening of the breathing muscles (less air flow available to power the voice) Ability to talk in full sentences is diminished</p> <p>Client begins to limit complexity and length of messages</p> <p>Client will need to use compensatory strategies to change the way he/she speaks to make self understood</p>	<p>Potential for social isolation due to issues with self-image and self-esteem</p> <p>Those who are having difficulty communicating verbally may need to be encouraged to use communication aids to reduce their frustration and that of their family/caregivers (Some may resist using communication aids.)</p> <p>Need to discuss concerns and establish Welfare and/or Continuing Powers of Attorney while the individual is able to communicate without significant difficulty</p> <p>Early introduction to palliative care services for support, information and education is beneficial to some pWMND and their families</p>	<p>Client frustration related to altered speech and communication challenges</p> <p>Family and caregiver frustration related to difficulty interpreting pWMND's speech</p> <p>Client's needs not being met due to caregiver's inability to understand the pWMND</p>	<p>Early introduction to range of communication options, low and high tech, including AAC (augmentative and alternative communication)</p> <p>Encourage pWMND to communicate important messages (letters, last wishes, legal documents) prior to deterioration of speech.</p> <p>Consider "voice banking" while still able to do so for use with some AAC equipment.</p> <p>Use of compensatory speech strategies by pWMND</p> <p>Ongoing assessment by Speech and Language Therapist and adaptation of assistive communication equipment AAC Alphabet or word boards (as backups to technology)</p>	<p>SLT, Consider referral to SCTCI/similar see pp 30/31 see pp 30/31 for assessment</p> <p>MND Scotland Care Team</p> <p>OT - adaptations for written communication</p> <p>Voice banking queries to info@smart-mnd.org</p> <p>MND Scotland equipment loan service – Lightwriter</p> <p>Office of the Public Guardian for Scotland for information and registration of Powers of Attorney- www.publicguardian-scotland.gov.uk</p>

MND Scotland Integrated Care Pathway – Communication

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 3: Incorporation of Augmentative-Alternative Communication				
<p>Moderate to severe dysarthria</p> <p>Communication may be limited to one-word responses or highly predictable messages (such as greetings)</p>	<p>Emotional challenges associated with decreased self-image (including avoidance of sexual relationships)</p> <p>Client and family may need assistance to plan for celebration of life or funeral arrangements</p>	<p>Increased difficulty using the telephone</p> <p>Increased loss of communication independence</p>	<p>Ongoing assessment by SLT for adaptation of assistive communication equipment</p> <p>Teach strategies for telephone communication, consider use of text phone.</p> <p>Use of 'spokesperson' (family member to assist in translation of pWMND's needs) in situations that require speech.</p>	<p>SLT</p> <p>SCTCI, or similar service</p> <p>MND Scotland equipment loan service</p>
Stage 4: Non-Functional Speech				
<p>Severe to profound dysarthria</p> <p>May be able to vocalise for emotional expression or with extreme effort</p> <p>Dependent on communication equipment</p>	<p>Increased social isolation as the disease progresses</p> <p>Individual and family may be concerned and anxious regarding financial obligations.</p> <p>Client may be withdrawn and/or frustrated due to lack of speech</p>	<p>Inability to communicate with family, friends and carers. Needs may be unrecognised.</p>	<p>Develop adequate and consistent yes/no' system (which may change rapidly)</p> <p>Develop eye gaze systems/E-tran frames</p> <p>Enable communication for pWMND on ventilators</p> <p>Reassess augmentative communication equipment and strategies</p> <p>Referral to hospice/day hospice for respite care</p>	<p>SLT</p> <p>SCTCI/similar see pp 30/31 see pp 30/31</p> <p>MND Scotland equipment loan service</p> <p>Respite and hospice programs</p> <p>Spiritual resources in the community</p>
Stage 5: Inability to Speak				
<p>Anarthria (inability to speak)</p>	<p>Lack of privacy in the home due to increased presence of health care providers and equipment</p> <p>Isolation and frustration related to pWMND's inability to make themselves understood or heard.</p> <p>Family members and caregivers may become frustrated, impatient and emotionally disengaged due to challenges of communication (i.e. time required to communicate)</p>	<p>Inability to initiate communication or communicate basic needs to family, friends and caregivers</p>	<p>Potential for use of 'eye gaze' system or other form of yes/no response (providing caregiver is able to discern between yes or no)</p> <p>Bulbar onset clients may reach this stage while they have good motor control and may be able to use an AAC device; Others reach this stage at the end-stage of the disease and may not have motor control for AAC usage. For them an 'eye gaze' system of communication is the only option, however, fatigue may be so great that eye-gaze computer systems may require too much effort to master.</p> <p>Increased involvement of Marie Curie/MacMillan Nurses.</p> <p>Assessment of spiritual needs and access to spiritual resources</p>	<p>SLT</p> <p>SCTCI/similar see pp 30/31</p> <p>MND Scotland equipment loan service</p> <p>Respite and hospice programs</p> <p>SW Department for funding</p> <p>Spiritual resources in the community</p>

MND Scotland Integrated Care Pathway – Respiratory Factors

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 1: Asymptomatic by day				
May have shortness of breath on vigorous exertion, however, most early symptoms manifest during sleep. Early indicators may include difficulty in rousing and unfulfilling sleep.	Loss associated with having to give up previously enjoyed physical activities due to other symptoms. Family sometimes attribute decreased energy as the pWMND not trying hard enough to keep up with activities. Memory deficits and poor concentration may arise due to excessive tiredness.	Minimal risks from breathing related issues, however other symptoms may pose different threats. Excessive tiredness might pose risks if operating equipment.	Baseline Pulmonary Function Testing (PFT) and Respiratory Assessment. May benefit from elevating the head of the bed (head and shoulders) at night.	Respiratory Medicine Unit at local hospital MND Care Team Member MND Scotland factsheets www.mndscotland.org.uk/information/factsheets 35 Breathing Matters www.mndcare.net.au/living-with-mnd www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware
Stage 2: Mild Symptoms				
Shortness of breath on moderate activity. Might be difficult to rouse in the morning and may nap more during the day. May start to have pooling of oral secretions. Cough is slightly diminished however; pWMND is able to move secretions with some effort. May have day time fatigue however, no morning headaches	Increased social isolation due to fatigue. Altered family relationships due to family being more involved in the person's care (e.g. lung volume recruitment, assisted cough, suctioning, positioning) Decreased self-image and self-esteem due to increased oral secretions. Early introduction to palliative care services for support, information and education is beneficial to some pWMND and their families.	Small risk of aspiration of secretions, food or drinks. Chest infections Hypoventilation Laryngospasm (spasm of the muscles in the throat causing closure of the vocal cords and airway obstruction)	Allow for rest periods during the day and plan activities to conserve energy. May benefit from elevating the head of the bed (head and shoulders) at night. Follow-up visit with respiratory specialists for follow-up PFTs. Introduction of lung volume recruitment (LVR) with bag (LVR bag) Introduction of LVR with cough-assist if indicated, early discussion of advance directives Consider medication to assist with the control of oral secretions May benefit from oral suctioning with rigid suction tip (Yankauer) Seasonal Cold symptoms need to be assessed by the family doctor. Avoid factors that may trigger laryngospasm (e.g. smoke, strong smells, aspiration, gastric reflux) Laryngospasm will pass on its own, but may be relieved by dropping chin to chest and swallowing, or by breathing slowly through nose. Prescription of antispasmodic medication may help with laryngospasm Reduce the incidence of gastric reflux by raising head of bed and using antacid medication	See the link called "Respiratory Protocols for SCI and Neuromuscular Diseases" at the following site www.irrd.ca/education/ use the drop-down menu to browse this topic Lung volume recruitment with resuscitation bag www.irrd.ca/education/slide.asp?RefName=e2r4&slideid=7 Manual assisted cough manoeuvre www.irrd.ca/education/slide.asp?RefName=e2r4&slideid=74 MND Care Team Specialist and/or local palliative care services plus Respiratory Medicine Unit at local hospital. www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Session 10 Breathing

MND Scotland Integrated Care Pathway – Respiratory Factors

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Stage 3: Moderate Symptoms				
<p>Voice volume is decreased.</p> <p>May be short of breath at rest or when lying down.</p> <p>Secretions may be more difficult to control.</p> <p>Cough is ineffective.</p> <p>May have raised blood carbon dioxide levels and shallow breathing at night leading to disrupted sleep, frequent waking, daytime headaches and daytime sleepiness. Poor concentration and memory can also result.</p>	<p>Changed family dynamics due to involvement in monitoring and assisting pWMND (as well as noise of ventilation equipment, if supplied, and irregular breathing during the night).</p> <p>Increased family concern over leaving the person alone in the home</p> <p>It is important to consider the respite needs of the family to avoid caregiver burnout and negative health effects</p> <p>Changes to intimacy and sexual relationships.</p> <p>Advance directives and Powers of Attorney should be in place in case of a health crisis.</p> <p>Increased concern regarding exposure to infections resulting in increased social isolation and avoidance of crowds</p> <p>Travel by plane unlikely due to problems associated with high altitudes/low air pressure</p> <p>Client and family may need assistance to plan for celebration of life or funeral arrangements</p>	<p>Same as in Stage 2 however, more pronounced</p> <p>Leaks around the mask and distension of the stomach by air if using NIPPV.</p> <p>Skin breakdown at pressure points if using NIPPV – ulceration and bacterial infections may follow.</p> <p>Some pWMND, who have dentures, might have difficulties due to pressure from the mask moving their dentures in their mouth.</p> <p>Respiratory failure</p>	<p>Increase frequency of LVR and assisted cough.</p> <p>Traditional physiotherapy secretion clearance techniques if LVR is ineffective</p> <p>Elevate head and shoulders at about 30 degrees if feeling short of breath when lying flat</p> <p>Follow-up visit with Respiratory Specialist and follow-up PFTs</p> <p>Review LVR with bag and assisted cough technique (may need a mask to replace the mouth piece) and necessity for medication/ suction to control oral secretions</p> <p>Introduction to mechanical inextufflator if available and LVR techniques are ineffective</p> <p>Discuss advance directives and ventilation choices with MND Care Team Member and Respiratory specialist.</p> <p>Ventilation education session with home ventilation team.</p> <p>Ventilation trial and initiation of nocturnal ventilation if this is available and is the pWMND's preferred choice, follow-up oximetry and parameter changes when necessary</p> <p>The breathing support interface (mask) may be difficult to adjust. Respiratory clinics may need to try more than one type of mask for effectiveness.</p> <p>Client should have access to a physician with palliative care expertise who is able to do home visits</p>	<p>Refer to resource section in Stage 2</p> <p>OT and/or Wheelchair Services technician to adapt wheelchair to mount ventilator, if supplied.</p> <p>SW and DN</p> <p>MND Scotland Care Team Member</p>
Stage 4: Advanced Symptoms				
<p>As in Stage 3 however more pronounced.</p> <p>Using breathing support unit more than 15 hrs per day</p> <p>Feeling short of breath while on breathing support</p> <p>Difficulty with breathing support interface and leaks</p>	<p>People are often unable to leave the home due to an increase in the need for respiratory support and associated equipment (consider portable equipment whenever possible).</p> <p>Frustration with difficulties associated with mounting the breathing support unit to an appropriate mobility aid.</p> <p>Lack of privacy in the home due to increased presence of health care providers and equipment.</p> <p>Re-visit advance directives to confirm they still reflect the pWMND's wishes.</p>	<p>As in Stage 3, however more pronounced</p> <p>Difficulty in holding the mouth interface for appropriate ventilation</p> <p>Gastric distension by air.</p> <p>Non invasive ventilation may not be appropriate if bulbar impairment is severe.</p>	<p>Follow-up visit with Respiratory Specialists, follow-up PFT, review LVR techniques.</p> <p>Add a back up battery for the breathing support unit, adjust parameters, perform an overnight oximetry and review interface fitting.</p> <p>Introduce day time mouth piece ventilation if possible.</p> <p>Review medication/suction to control secretions.</p> <p>Increased involvement of visiting and shift nursing.</p> <p>Assessment of spiritual needs and connecting to spiritual resources.</p> <p>Increased involvement of palliative care specialists</p>	<p>Refer to resource sections in Stage 2 and 3 Mouth piece ventilation / LVR with volume ventilator</p> <p>MND Care Team Specialist.</p> <p>Respite and hospice programs</p> <p>McMillan/Marie Curie nurses.</p> <p>Spiritual resources in the community</p> <p>Palliative care physician</p>

MND Scotland Integrated Care Pathway – Fatigue and Insomnia

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Fatigue				
<p>Physical tiredness and lack of stamina. Inability to do even light physical tasks without experiencing physical exhaustion.</p> <p>(Can arise due to one or all of the following: the few working muscle fibres having to do the job of the whole muscle; inadequate nutritional intake, respiratory insufficiency or a side effect of riluzole. See the sections on Mobility, Respiratory Factors and Eating Drinking and Swallowing for possible interventions appropriate to the cause,)</p>	<p>Withdrawal from attempting physical activities.</p> <p>Depression due to realisation of limited physical abilities as compared to when healthy.</p> <p>Frustration due to limitations.</p> <p>Overwhelming feeling of tiredness to the exclusion of other activities including thought.</p> <p>Increased family concern over leaving the person alone in the home</p> <p>Consider the respite needs of the family to avoid caregiver burnout and negative health effects as they take on more physical activities.</p> <p>Changes to intimacy and sexual relationships.</p>	<p>Social isolation.</p> <p>Falls, sprains, strains - both to person with MND and to carer.</p> <p>Depression</p>	<p>Energy conservation strategies (see page 4.)</p> <p>Planning in advance to do physical activities when the person has most energy.</p> <p>Prioritising activities.</p> <p>Resting between physical activities.</p> <p>Using assistive aids that help reduce energy expenditure when possible, e.g. wheelchair.</p> <p>Involve local social work department's home care services.</p>	<p>MND Care Team Specialist, OT, Physiotherapist, Rehab specialist, Respiratory nurse/ consultant</p> <p>www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Session 19</p>
Insomnia				
<p>Difficulty in either getting to sleep or frequent awakening during sleep.</p> <p>Other signs might include unrefreshing sleep, difficulty in wakening, frequent daytime napping and morning fatigue and headache.</p>	<p>Daytime tiredness, poor concentration, lethargy short term memory deficits, confusion, irritability.</p> <p>Extreme emotions and mood swings.</p> <p>Consider also anxiety and depression.</p>	<p>Increased risk of accidents due to poor coordination.</p> <p>May not recognise, or may react inappropriately, to the risks or dangers of unfamiliar situations.</p>	<p>Identify the root cause of the problem and treat accordingly.</p> <p>Common causes include anxiety, depression, ineffective breathing/hypoventilation, sleep apnoea, joint or muscle pain, positional discomfort (especially when unable to move), saliva or other secretions and medication.</p> <p>In addition, avoid over-exertion before bed and develop regular routines at bedtime,</p> <p>Avoid both heavy meals and caffeinated drinks (tea, coffee, cola and energy drinks) in the evening.</p>	<p>GP, MND Care Team Member, District Nurse, Hospital Consultant</p> <p>www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 Sessions 12 & 19</p>

MND Scotland Integrated Care Pathway – Bowel and Bladder

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Constipation				
Infrequent toileting, hard difficult to pass stools, discomfort or straining, can also be accompanied by stomach ache and cramps, bloating, loss of appetite and nausea	Embarrassment. Depending on the person's abilities there may be loss of self esteem if help is required from a carer.	Anal fissure Diverticulitis and associated risks Haemorrhoids Rectal Prolapse	Attempt to identify the underlying cause. Common causes are:- Lack of fibre Insufficient fluid intake Lack of physical activity A change in eating patterns Side effects from medication, particularly opioids Anxiety/stress/depression Ignoring the urge to go to the toilet Lack of privacy when going to the toilet	GP Advice from a dietitian about fluid and dietary intake and managing constipation Advice from a physiotherapist about the most effective use of the abdominal and respiratory muscles Strategies for ongoing review Ongoing monitoring and advice from a community nurse
Diarrhoea				
Watery stools, often associated with urgency to go.	Embarrassment, withdrawal from social situations. Anxiety if the condition becomes chronic.	Dehydration and electrolyte loss if long term. Faecal contamination of clothing, bedding and furniture. Transfer of coliform bacteria contamination from hands to other surfaces Food poisoning. May sometimes be due to faecal compaction as a result of constipation.	Attempt to identify the underlying cause and treat appropriately. Common causes included diet, reactions to some drugs (such as antibiotics), infections and food poisoning.	Discuss with GP Advice from a dietitian about fluid and dietary intake. Ongoing monitoring and advice from a community nurse
Incontinence				
Unintended, uncontrolled defecation or urination	Embarrassment, withdrawal from social situations. Loss of self esteem, anxiety.	Faecal and urinary contamination of clothing, bedding and furniture. . Transfer of coliform bacteria contamination from hands to other surfaces Food poisoning.	Incontinence is rarely a result of MND affecting the sphincters, more normally it results from an inability to push due to weak abdominal and respiratory muscles. Laxatives and stool looseners or physical evacuation may therefore be necessary.	Ongoing monitoring and advice from a community nurse or GP
Urinary Urgency				
Sudden and urgent need to urinate	Embarrassment, withdrawal from social activities	Contamination of clothing, bedding, household fittings.	May be due to urinary tract infection, particularly if incontinence pads are worn. Can also be due to other causes.	Discuss with GP
Poor Toileting Hygiene				
Soiled clothing or linen, smell.		Contamination of clothing, bedding and furniture. Transfer of coliform bacteria contamination from hands to other surfaces Food poisoning.		Advice from an occupational therapist about helpful aids and equipment

MND Scotland Integrated Care Pathway – Cognitive Change

Although traditionally regarded as unrelated entities, it is increasingly clear that MND and frontotemporal lobar degeneration (FTLD or FTD) are neurodegenerative conditions with overlapping clinical and neuropathological features. That there is an association between Amyotrophic Lateral Sclerosis (ALS), the most common form of MND, Cognitive Change and Behavioural Change is now well established. Up to 15% of ALS patients meet the criteria for Frontotemporal Dementia and a further 35% have a mild cognitive impairment or other behavioural change.

At the time of writing, two genes, TDP-43 and FUS/UTL, are implicated in both ALS and FTLD. TDP-43 positive pathology, where TDP-43 deposits are found within cytoplasmic and nuclear inclusions is present in virtually all patients who have FTLD associated with ALS. However, the deposits of the protein made by this gene are found in different sub-cellular locations of the neurone in FTLD when compared to those cases of ALS in which the gene has been implicated as a causative agent. Cognitive & Behavioural change in MND is generally agreed to form a spectrum ranging from mild changes in perception occurring later in the illness, often detectable only by specific testing, through aphasia, which can occur at almost any stage of the illness, to a more severe familial condition in which a dementia that begins with behavioural changes can precede the onset of ALS symptoms by six months or longer.

One model, (see, for example, Lillo and Hodges J. Clin. Neurosc. 16: pp1131-1135, 2009) proposes that FTLD in MND can present as either a behavioural variant (bvFTD) or a language-onset variant

and that the language onset variant can manifest as either Semantic Dementia (SD) or Progressive Nonfluent Aphasia (PNFA).

In common with the other symptoms of MND there is no fixed pattern of development of the symptoms associated with Cognitive and Behavioural Change that is applicable in all cases. Instead most ALS-FTD patients will develop some of the features of one of the subsets of ALS-FTD (above) while very few will develop all of the features of that subset.

It is important to consider that patients with unaddressed respiratory deficiencies may show signs of confusion, lack of concentration, listlessness and poor memory due to the cumulative effects of weeks of sleep disturbances as a result of sleep hypoxia. It is very probable that such respiratory deficiencies will exacerbate any symptoms arising from cognitive or behavioural changes. In consequence it is important to eliminate respiratory insufficiency as a contributing factor to the person's cognitive or behavioural changes before attempting any psychological assessment.

Excellent suggestions on ways to manage cognitive and behavioural change are available on-line at:- www.mndcare.net.au/overview/online-training-for-service-providers/mnd-aware/mnd-aware-symptom-management-sessions-10-to-19 See Sessions 16 Cognition & 17 Emotional Lability

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Behavioural Changes				
These fall within the range typical of FTD and may include apathy, restlessness, impulsiveness, self-centredness, reduced concern for the feelings of others, perseveration (fixed on one activity or routine), social disinhibition, increased irritability, emotional blunting, food cramming (especially sweet foods), stereotypical behaviours and compulsive behaviour (taking advice or suggestions as imperatives).	Reluctance to become involved in activities. Unpredictability of actions (impulsivity); may make inappropriate actions or comments, may develop fixed behavioural routines and insist others should also comply with these. May appear demanding or controlling.	Alienation of friends, family and others who may be offended due to not understanding the origins of these behaviours. Weight gain if food cramming. Social problems, e.g. Police, due to disinhibited and sometimes sexually overt behaviours or comments.	Education of all involved of the nature and scope of these behavioural changes. Distraction of the patient from the troublesome or concerning behaviour. Manage the environment to remove "triggers" for the behaviour.	MND Scotland Care Team, Community Psychiatric Nurse, GP, DN, MND Scotland's "Problem Solving Approach" booklet.
Semantic Aphasia				
Loss of names for things and impaired understanding of, concepts, words, objects, or facial expressions. The patient frequently can't "find the right word" and has fluent, empty speech with substitutions such as "thingy", and "what's it called", but the grammatical aspects are preserved. Naming is impaired with errors (such as "animal" or "horse" for zebra). Patients fail to understand less frequent words and fail on a range of tasks such as matching words to pictures and matching pictures according to their meaning. Repetition of words and phrases is normal even though patients are unaware of their meaning. Day-to-day memory (episodic memory) with good visuospatial skills and non-verbal problem-solving ability are relatively preserved, at least in the early stages unlike in Alzheimer's disease. MRI imaging in semantic aphasia shows a typically asymmetric pattern of anterior and inferior temporal lobes (left greater than right).	Difficulties describing where the person has been, what they have done, or what they want to do. Frustration or embarrassment due to recognition by the person themselves that they are unable to name objects or places. May fail to recognise the emotional state of others and not moderate themselves accordingly. Difficulty in understanding what is being said, particularly when being instructed in new ways of doing things, e.g. how to operate new equipment.	Inappropriate responses arising from frustration, e.g. withdrawal. Misunderstandings by others of what the person is trying to communicate. Difficulty in learning new ways of doing things or operating new equipment due to not understanding instructions if unfamiliar words are used.	Education of all involved with the person of the nature and scope of language changes. Consider how MND can progress when making suggestions for interventions for other symptoms so that initial interventions are built upon later, rather than being replaced by new and unfamiliar instructions, equipment or techniques which require complete relearning.	MND Scotland Care Team, GP, DN, MND Scotland's "Problem Solving Approach" booklet.

MND Scotland Integrated Care Pathway – Cognitive Change

Presentation	Psychosocial Considerations	Potential Risks	Interventions	Supportive Resources
Nonfluent Aphasia				
Expressive language abilities gradually diminish e.g. the small grammatical words that allow sentence construction are lost, impairments develop in sound-based aspects of language, This leads to non-fluent, poorly constructed, and poorly articulated speech with errors (e.g. “sitter” for sister or “fencil” for pencil). Repetition of polysyllabic words and phrases is impaired but, unlike semantic aphasia, word comprehension and object recognition are well preserved. MRI changes are much more subtle than in semantic aphasia with widening of the left Sylvian fissure. These distinctions are clear when patients first present with symptoms, but with progression of the disease, most patients manifest both behavioural and language features.	Reduced language skill Difficulty using language Difficulty understanding language Difficulty finding the right words	Misunderstandings by others of what the person is trying to communicate. Difficulty in learning new ways of doing things or operating new equipment due to not understanding instructions if unfamiliar words are used.	Education of all involved with the person of the nature and scope of language changes. Consider how MND can progress when making suggestions for interventions for other symptoms so that initial interventions are built upon later, rather than being replaced by new and unfamiliar instructions, equipment or techniques which require complete relearning.	MND Scotland Care Team, GP, DN, MND Scotland’s “Problem Solving Approach” booklet.
Emotional Lability				
Commonly associated with those affected by bulbar symptoms EL manifests as uncontrolled expressions of emotion, e.g. laughing or crying. In states of high emotion one may blend into the other leading to an inappropriate or exaggerated response for the circumstances. For example an unexpected small gift might be greeted with laughter of delight ending with tears of gratitude. There may also be a “crossing over” of emotional responses so that tears may greet a jocular remark and laughter a report of a tragedy.	Social embarrassment, reluctance to enter social activities or meet people.	Social awkwardness, failure to mention this symptom to GP or other professionals due to embarrassment and concerns over how it might be perceived.	Some drug interventions are available.	GP, DN or MND Care Team Member for advice. See “A Problem Solving Approach” for drug recommendations.

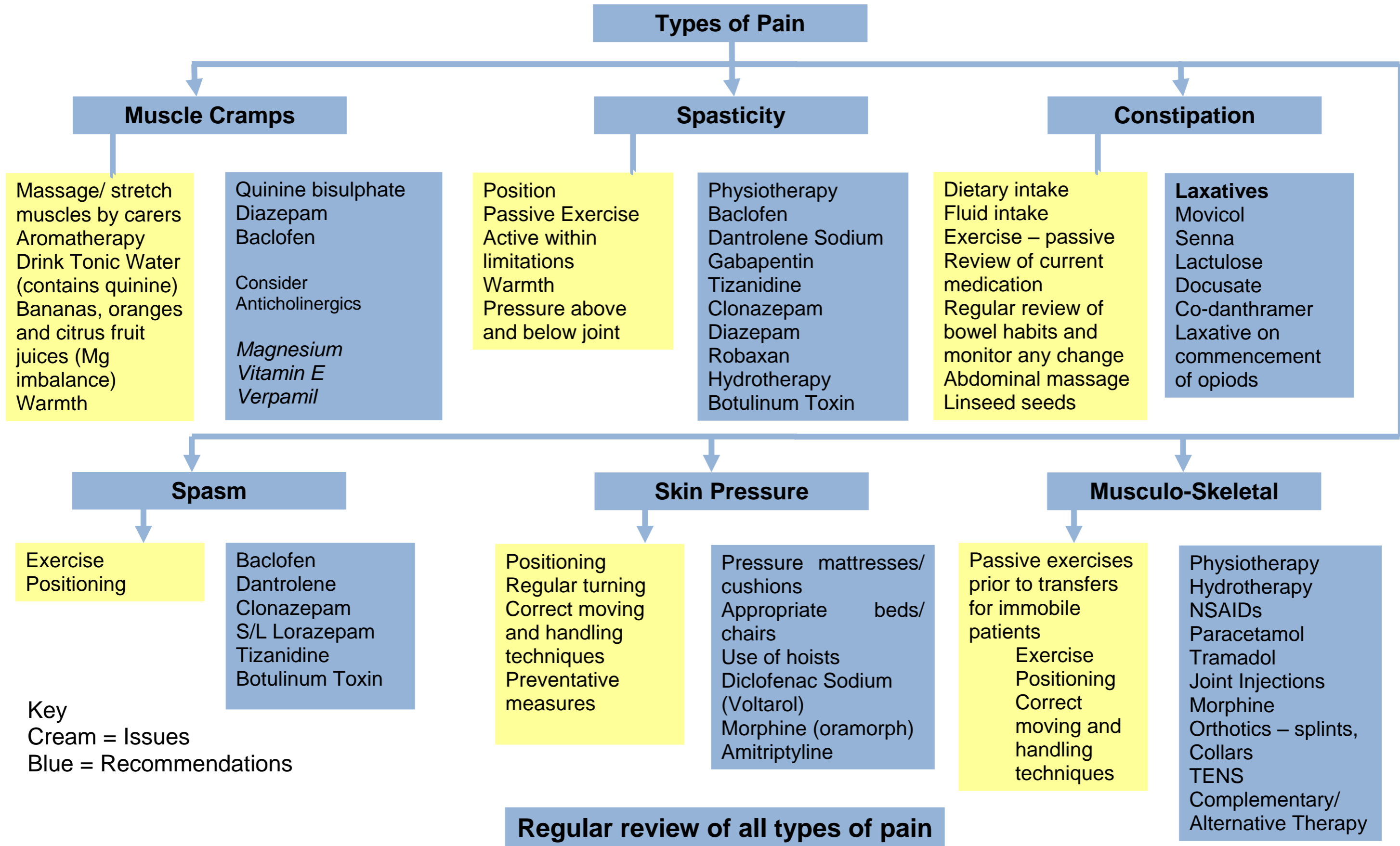
MND Scotland Integrated Care Pathway – Sexuality

The need for touch, intimacy and closeness is never lost as a result of disability. Sexual expression of love and communication in couples is a very important part of who we are. Amyotrophic Lateral Sclerosis (MND) does not usually affect a person’s ability to have a sexual relationship, including pleasure from tactile sensations, erection, and orgasm, not to mention the pleasure derived from pleasing another person.

Sometimes, however, enjoyment of a sexual relationship may be hampered by symptoms of MND, such as excessive fatigue, joint pain, arm or leg stiffness or bothersome fasciculation. Some medications prescribed to help with MND symptoms may also have an effect on sexual functioning.

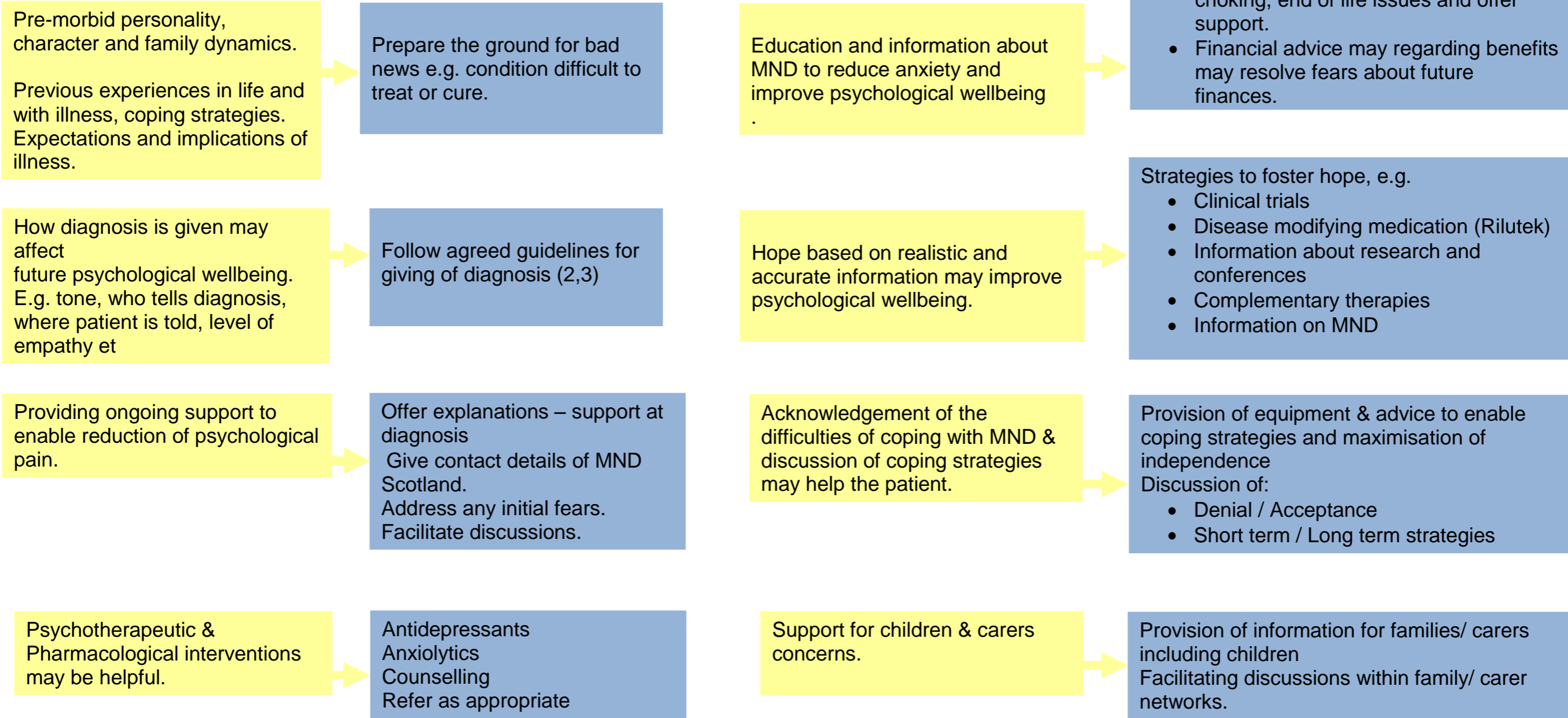
As the disease causes more weakness throughout their body, people with MND may worry that they are becoming less attractive to their partners. The partner may refrain from intimacy because they are afraid of hurting the person with MND during sexual play. It is important to maintain good communication about what works and what does not work for you and your partner.

Many options are available to the individual and/or couple to manage these changes. If you have any questions about how you can maintain enjoyable intimate relationships or if you begin to experience difficulty with some aspect of your sexual well being, please be assured that you can discuss this with any of the health care professionals on the MND clinical team.



MND Scotland Integrated Care Pathway – Psychological Pain

The approach to psychological pain may not be as simple as identify pain – treat pain – absence of pain. Psychological pain can take many forms, e.g. fear, anger, frustration, stress, loss of control, anxiety, depression. Psychological pain varies greatly between individuals. It may not be expressed as openly as physical pain due to cultural restraints and may be difficult for people with MND to admit fear or depression. It must be accepted that a certain amount of pain may be unavoidable and may need to be worked through before improvement. It is also necessary to consider the psychological pain of both family and lay professional carers.

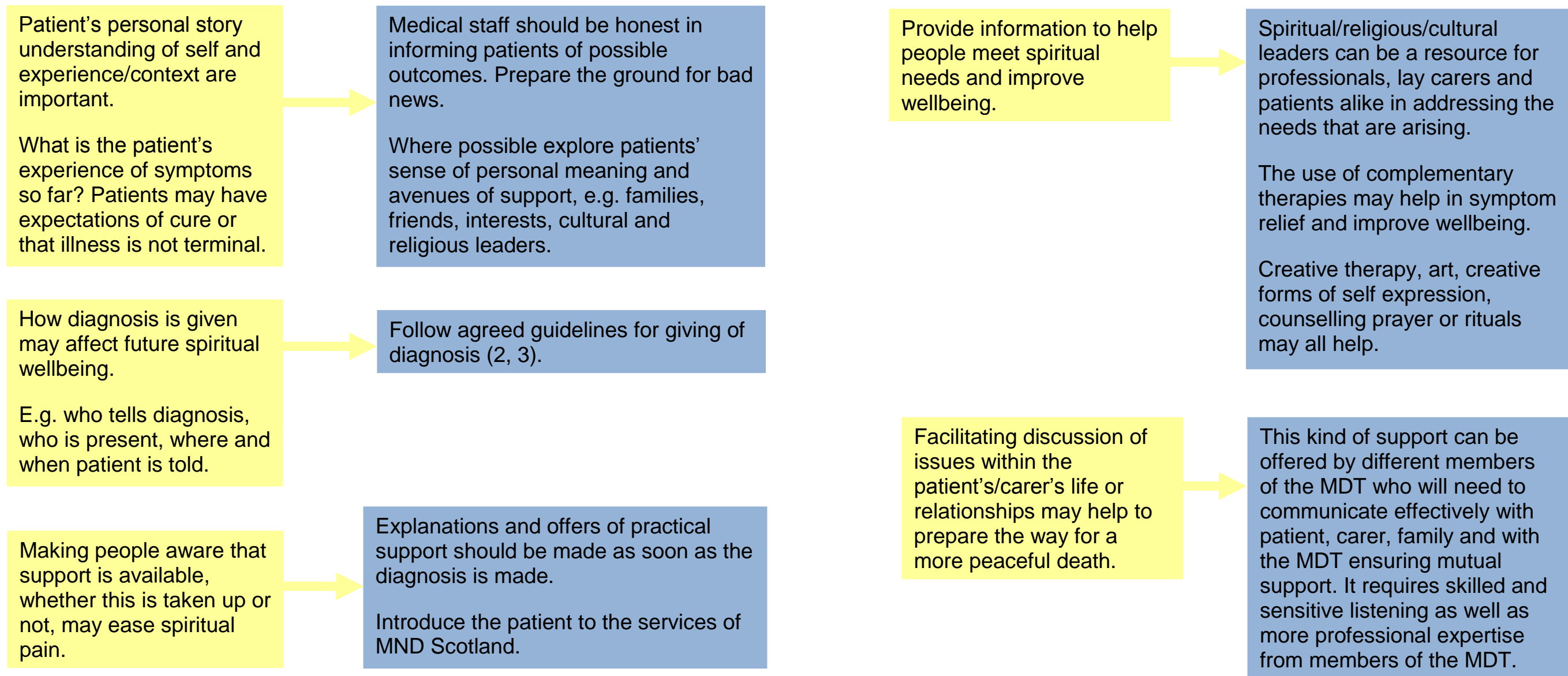


Spirituality may be defined as, a search for meaning within a life experience and will encompass a patient’s understanding of self in relationship with others (for example: people, nature, God)

There is an overlap with the psychological and spiritual pain. Spiritual pain may take many forms and can be voiced to any member of the team both lay and professional. It may be expressed in the question “Why me?”, but may also be manifested as fear, grief, anger, regret, stress, loss of control, anxiety, depression, as well as specifically religious or cultural concerns. In times of crisis/vulnerability, a reassessment of one’s spiritual values is common.

Spiritual pain varies between individuals and may be expressed in different ways according to culture and background.

Unlike physical pain a certain amount of spiritual pain may be unavoidable, and spiritual pain may need to be worked through in order for personal growth/integration of the experience to take place. Thus the approach to spiritual pain may not be as simple as: Identify – treat pain – absence of pain. It is also necessary to consider the spiritual pain of family, lay and professional carers.



- 4.9 People affected by neurological conditions have ongoing access to self-management options.
- 4.10 Patients with advanced conditions or complex needs have access to assessment and treatment in their place of residence by a member of the neurology multidisciplinary team where they are unable to access services at hospitals or clinics.
- 4.11 Patients with neurological conditions have access to equipment for assisting with daily living where that equipment is normally provided by NHS Scotland.
- 4.12a Palliative care is provided for patients with neurological conditions, their family and carers, as required throughout the course of their illness, and in accordance with the wishes of the patient.
- 4.12b Specialist palliative care is provided for patients with complex needs.
- 4.12c Patients with neurological conditions are encouraged to discuss advance care planning, when clinically appropriate.

Standard 11 “Access to specialist motor neurone disease services

Standard statement 11

An effective and comprehensive motor neurone disease service is available and offered across all NHS boards.

Rationale

Patients with motor neurone disease receive better quality care when diagnosis, treatment and therapy are delivered within a specialist multidisciplinary team in their local NHS board

Essential Criteria

- 11.1a Patients with suspected MND are referred to a neurologist.
- 11.1b Patients with clinically definite or clinically probable MND are referred to a defined MND service
- 11.2 The multidisciplinary team consists of, as a minimum, a doctor who specialises

in MND, a regional care specialist, the patient and a carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services:

- Physiotherapy
- Occupational therapy
- Speech and language therapy
- Dietetics
- Pharmacy services
- Mental health services

- 11.3 The NHS board provides rapid access to demonstrably effective care pathways covering all aspects of the illness, including links to specialist palliative care and respiratory medicine, gastrostomy services and social services.

Standard 12: Diagnosis of motor neurone disease

Standard statement 12

Patients with suspected motor neurone disease have their diagnosis confirmed by a neurologist, with access to appropriate investigation resources and the specialist motor neurone disease multidisciplinary team.

Rationale

Timely access to necessary investigations is essential to an efficient and effective diagnostic

process for patients with suspected motor neurone disease.

Following diagnosis, patients benefit from rapid access to a motor neurone disease

- 12.1 On request from a neurologist, patients with suspected MND have access to relevant investigation resources including imaging and neurophysiology within 20 working days.

- 12.2a The diagnosis of MND is confirmed and conveyed to the patient by a neurologist.
- 12.2b Patient review, after neurophysiology and imaging takes place, is achieved within 15 working days.
- 12.3a The MND regional care specialist makes contact with the patient within 2

working days of confirmation of the diagnosis.

- 12.3b Patients with MND and their carers are offered contact details for specialist support services provided by voluntary sector organisations.

Standard 13: Ongoing management of motor neurone disease

Standard statement 13

Patients with motor neurone disease and their carers are offered a wide range of support at all stages of their condition.

Rationale

Motor neurone disease is a degenerative condition that can be rapidly progressive. Patients with motor neurone disease have complex needs that can affect all aspects of their lives.

Maintaining the patient's ability to communicate is essential. Every effort should be made to encourage advance care planning to ensure patient autonomy during the course of the disease.

Communication within the motor neurone disease services, throughout all stages of the condition, is central to delivering a better quality of life for the patient with motor neurone disease and their carers.

There is evidence that nutritional and respiratory support improves the quality of life for the patient with motor neurone disease and their carers.

Essential criteria

- 13.1a A needs assessment is offered to patients with MND at all stages of the patient's condition. The assessment is updated as the disease progresses.
- 13.1b A needs assessment is offered to those caring for people with MND at all stages of the patient's condition. The assessment is updated as the disease progresses.
- 13.1c At all times an identified individual is allocated responsibility for coordinating the delivery of care relevant to the assessed needs.
- 13.2a The service assesses and meets the communication needs of patients with MND at all stages of their condition.
- 13.2b The service assesses and meets the nutritional needs of patients with MND at all stages of their condition.
- 13.2c The service assesses and meets the respiratory needs of patients with MND at all stages of their condition.

APPENDIX A

Key Service Resources in Scotland for Information and MND Management

The person's family GP and the MND Scotland Care Team Members can involve many of the commoner resources mentioned in the tables above, such as District Nurses, Occupational Therapy, Physiotherapy and Speech and Language Therapy.

The list, below, contains details of more specialist or localised resources, which people with MND or their carers might find useful, and a general description of their role.

Resource	Role and Mandate	Contact Information
MND Scotland	<p>MND Scotland provides a range of services to support people and their families. These services include:</p> <ul style="list-style-type: none"> • Family information evenings for the recently diagnosed to give those affected and their families an opportunity to learn more about the disease and resources available to help them. • Equipment Loan service, designed to fill the gap between the need for an item need being identified and someone's own equipment being supplied by the local authority or NHS. • Welfare rights and benefits service; introduced in 2009 the service has "alternative office" status, which allows your claim to be backdated to when we first deal with it, rather than when it arrives at the appropriate DWP office. You can mandate us to speak to the DWP and other agencies on your behalf in order to handle a benefits claim or application for other welfare rights such as a "Blue Badge" for disabled drivers. • Information and library service to provide detailed information on less common resources sometimes needed by people with MND. The service has links to other providers of information on health and disabled facilities across the country ranging from toilets to holiday homes, specialist equipment and other specialist services. • Counselling service to meet the emotional needs of everyone affected by MND, including carers and family members. 	<p>74/76 Firhill Road Glasgow, G20 7BA. Tel 0141 945 1077 Email: info@mndscotland.org.uk</p>
MND Scotland Care Team	<p>MND Scotland supports the salaries of six care team members based at the principal centres for neurology across Scotland. All newly diagnosed cases of MND should be referred to the appropriate care team member for the area in which the patient resides. Care team members act as sources of specialist advice and experience to help ensure appropriate and timely support is provided by Local Authority and NHS staff to meet the needs of people affected by MND.</p>	<p>See inside front cover of this booklet.</p>

Resource	Role and Mandate	Contact Information
SCTCI	<p>The Scottish Centre of Technology for the Communication Impaired (SCTCI) exists to provide a high quality tertiary level of AAC service to people referred to SCTCI from 10 of the 14 NHS Boards in Scotland: Ayrshire and Arran, Borders, Dumfries and Galloway, Forth Valley, Highland, Grampian, Greater Glasgow and Clyde, Lanarkshire, Tayside and Western Isles</p> <p>SCTCI staff work throughout Scotland with both children and adults who have significant limitations to their ability to communicate through speech. Their aim is to help to improve an individual's communication opportunities through the use of Augmentative and Alternative Communication (AAC).</p> <p>AAC is the term used to describe methods of communication which can be used to supplement the more usual methods of communication when they are impaired. AAC techniques and strategies include the use of unaided systems such as signing and gesture as well as aided techniques ranging from picture charts to the most sophisticated computer technology currently available.</p>	<p>SCTCI is located within the WestMARC Building at the Southern General Hospital 1345 Govan Road Glasgow G51 4TF</p> <p>Tel:0141 201 2619 Fax:0141 201 2618 Email:sctci@ggc.scot.nhs.uk</p>
TORT -Tayside Orthopaedic and Rehabilitation Technology Centre	Provides Orthotics, Prosthetics and Wheelchairs for the area covered by NHS Tayside	Tayside Orthopaedic and Rehabilitation Technology Centre Ninewells Hospital Dundee DD1 9SY Telephone: 01382 496301 Fax: 01382 496322
EATS	Electronic Assistive Technology Service provides a similar service to SCTCI in the NHS Tayside area.	EATS Ninewells Hospital Dundee DD1 9SY Telephone: 01382 496286 Email: j.r.linskill@dundee.ac.uk
Ayrshire & Arran AAC Resource	The SLT from the AAC resource provides assessment services and short and long term loans of equipment, support and training to the client, carers, family members, and to therapists and other professionals. Training is also provided to NHS staff and education across the three local authority areas covered by NHS Ayrshire and Arran. The SLT from the AAC Resource provides ongoing technical support and maintains a loan bank of equipment.	Room 156 Admin Block, Ayrshire Central Hospital, Kilwinning Road, Irvine, KA12 8SS Tel: 01294 323 528 Email: linda.page@aapct.scot.nhs.uk

Fife Assessment Centre for Communication Through Technology	The Fife Assessment Centre for Communication through Technology (FACCT) provides a Fife-wide service to children and adults whose communication ability is limited due to a severe oral communication difficulty. This may have resulted from conditions present from birth, such as cerebral palsy or learning disabilities, or develop later in life, from conditions such as head injury, motor neurone disease or stroke. An individual with a communication difficulty can be referred through an open referral system.	Sandra Miller, Fife Council, Auchterderran Centre, 14 Woodend Road, Auchterderran, Lochgelly KY5 0NE Tel:08451 55 55 55 + Ext 44 20 00
Keycomm	<p>KEYCOMM'S AIMS</p> <p>To provide a multi disciplinary Service for people with communication disorders who reside in Edinburgh and the Lothians [Midlothian, East and West Lothian]</p> <p>To recommend appropriate technology and support</p> <p>To provide training and information for professionals, carers and users about the use and application of technology</p> <p>To provide a long term support service for all those involved with Communication Technology</p>	Keycomm Resource Centre Lothian Communication Technology Service 1C Pennywell Road Edinburgh EH4 4PH Tel: 0131 311 7130
Westmarc (West of Scotland Mobility and Rehabilitation Centre)	<p>Areas served: Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Lanarkshire, Highlands (Argyll & Bute only), Greater Glasgow and Clyde</p> <p>Services: Wheelchair and Seating Service, Prosthetics, Environmental Controls, Neuro-biomechanics</p>	WestMARC Southern General Hospital 1345 Govan Road Glasgow G51 4TF Tel: 0844 811 3001 (Wheelchairs and Seating Monday to Friday 8.45 am to 4.15 pm and answer-phone) Fax: 0141 201 2649 Email: westmarc@ggc.scot.nhs.uk
Highland Acute Hospitals NHS Trust Wheelchair Service	Areas covered: Western Isles Health Board, Highland Health Board, except Argyll & Bute	Wheelchair Service Department of Medical Physics Raigmore Hospital Old Perth Road Inverness IV2 3UJ Tel: 01463 04167/9 Fax: 01463 705717
NHS Grampian Mobility and Rehabilitation Services	Areas Covered Grampian Health Board, Orkney Health Board, Shetland Health Board	Mobility and Rehabilitation Services Woodend Hospital Eday Road Aberdeen AB15 6LS Tel: 01224 556840 Fax: 01224 556842

Resource	Role and Mandate	Contact Information
Lothian Primary Care Trust Mobility Centre	Borders Health Board, Fife Health Board, Lothian NHS Board	Mobility Centre Astley Ainslie Hospital 133 Grange Road Edinburgh EH9 2HL Tel: 0131 537 9177 Fax: 0131 537 9176
North Glasgow NIV and Assisted Ventilation Service	North Glasgow	Dr SW Banham Gartnavel General Hospital Dr E Livingston Glasgow Royal Infirmary
Lothian Home Ventilation Service	Edinburgh and Lothians, Scottish Borders, Forth Valley and Fife	Dr Ian S Grant Home Ventilation Service Critical Care Department Western General Hospital Edinburgh
Scottish Driving Assessment Service	The service offers driving assessment for people who wish to commence, resume or continue driving after illness or injury, as well as advice on vehicle modifications to enable safe driving or passenger travel for those with a disability. Although based at the Astley Ainslie Hospital in Edinburgh, assessments are also carried out via a mobile service which visits hospitals in Dundee, Aberdeen, Inverness, Paisley, Irvine and Dumfries.	Marlene Mackenzie, Development Manager, Scottish Driving Assessment Service, Astley Ainslie Hospital, 133 Grange Loan, Edinburgh EH9 2HL Tel. 0131 537 9192 email: Marlene.Mackenzie@nhslothian.scot.nhs.uk

Appendix B Palliative Care Resources

Health Board Area	Resource	Services Offered
National Childrens' Hospice	Rachel House Children's Hospice Avenue Road Kinross, KY13 8FX Tel: 01577 865777 www.chas.org.uk/rachel-house	
National Childrens' Hospice	Robin House Children's Hospice 2 Boturich Road, Balloch Dunbartonshire G83 8LX Tel: 01389 722055 www.chas.org.uk/robin-house	
Ayrshire & Arran	Ayr Hospital, Dalmellington Road, Ayr, KA6 6DZ 01292 Tel 01292 610555 ext 4286	Hospital Support Team, Ayrshire, Arran, KA postcodes
Ayrshire & Arran	The Ayrshire Hospice 35 Racecourse Road, Ayr, KA7 2TG Tel: 01292 269200 www.ayrshirehospice.org/	20 beds, Home Care, Day Care, Hospital Support Team, Bereavement Service
Borders	Borders Macmillan Centre, Borders General Hospital, Melrose, TD6 9BS Tel 01896 828282, 01896 826888	8 Beds, Home Care, Hospital Support Team, Bereavement Service, Scottish Borders, TD postcodes
Dumfries & Galloway	Annan Macmillan Service, Annan Clinic, Charles Street, Annan, DG12 5AG Tel 01461 205218	Home Care, Annandale & Eskdale
Dumfries & Galloway	Dumfries Specialist Palliative Care Service, Alexandra Unit, Dumfries & Galloway Royal Infirmary, Bankend Road, Dumfries, DG1 4AP Tel 01387 241347	8 Beds, Day Care, Hospital Support Team, Bereavement Service, Dumfries & Galloway, DG1, to DG16
Dumfries & Galloway	Newton Stewart Macmillan Service The Health Centre, Creebridge, Newton Stewart, DG8 6NR, Tel 01671 402587	Home Care, Hospital Support Team, Bereavement Service, Wigtownshire, DG8, DG9
Fife	Fife Palliative Care Service, Cedar House, Willow Drive, Kirkcaldy Fife, KY1 2LF Tel 01592 648072, 01334465822	Home Care and Bereavement Service, Fife, KY, DD6
Fife	Queen Margaret Hospital, Ward 16 Whitefield Road, Dunfermline, KY12 0SU Tel 01383 627016	9 beds, Hospital Support Team, Bereavement Service, West Fife
Fife	Hospice Unit St Andrews Community Hospital Largo Road St Andrews KY16 8AR, Tel 01334 468671	4 Beds, Hospital Support Team, Bereavement Service
Fife	Victoria Hospice, Hayfield Road, Kirkcaldy Fife, KY2 5AH, Tel 01592 648072	10 Beds, Day Care, Hospital Support Team, Bereavement Service, Central Fife
Forth Valley	Palliative Care Team, Forth Valley Royal Hospital Stirling Road Larbert Stirlingshire FK5 4WR, Tel 01324 566000	Hospital palliative care service available Forth Valley, FK8, FK9, FK10
Forth Valley	Strathcarron Hospice Randolph Hill, Denny, Stirlingshire, FK6 5HJ Tel: 01324-826222 www.strathcarronhospice.org	
Grampian	Aberdeen Hospital Specialist Palliative Care Team, Main Corridor Lower Level Aberdeen Royal	Inpatients, Outpatients & Home care, Grampian

	Infirmiry, Foresterhill, Aberdeen, AB25 2ZN Tel 01224 554001	
Grampian	Banff MacMillan Service , The Health Centre, Clunie Street, Banff, AB45 1HY, Tel 01261 819182	Home Care & Hospital Support Nurse, Banff, Macduff, Portsoy, Turriff
Grampian	Roxburghe House Aberdeen Department of Palliative Medicine, Ashgrove Road, Cornhill Site, Aberdeen, AB25 2ZH Tel: 0845 456 6000	
Grampian	Elgin The Oaks Palliative Day Care Centre, Morriston Road, Elgin, IV30 6UN Tel: 01343 555104	Day Hospice and Home care
Grampian	Fraserburgh MacMillan Service, Fraserburgh Hospital, Fraserburgh, AB43 9NH Tel 01346 585274	Home Care, Beds if needed, Fraserburgh, Crimond, Hatton, Cruden Bay
Grampian	Peterhead Community MacMillan Nurse Peterhead Health Centre, Links Terrace, Peterhead, Aberdeen, AB42 6XA 01779 482568	Home Care, Peterhead, Mintlaw, New Pitsligo, New Deer, Crimmond, Hatton, Cruden Bay
Greater Glasgow & Clyde	Accord Hospice , Morton Avenue, Paisley, PA2 7BW Tel: 0141-581.2000 www.accord.org.uk	8 beds, home care, day care, bereavement service Renfrewshire
Greater Glasgow & Clyde	Ardgowan Hospice , 12 Nelson Street, Greenock, PA15 1TS Tel: 01475 726830 www.ardgowanhospice.org.uk	8 beds, home care, day care, bereavement service, Inverclyde and Renfrewshire
Greater Glasgow & Clyde	Glasgow Marie Curie Hospice , 133 Balornock Rd, Glasgow G21 3US Tel. 0141 557 7400 //hospiceglasgow.mariecurie.org.uk/	35 beds, home care, day care, bereavement service,
Greater Glasgow & Clyde	Prince & Princess of Wales Hospice , 71 Carlton Place, Glasgow, G5 9TD Tel: 0141 429 5599 www.ppwh.org.uk	14 beds, home care, day care, bereavement service,
Greater Glasgow & Clyde	St Margaret of Scotland Hospice , East Barns St., Clydebank, G81 1EG, Tel: 0141 952 1141 www.smh.org.uk	30 beds, home care, day care, bereavement service,
Greater Glasgow & Clyde	St. Vincent's Hospice Midton Road, Howwood, Renfrewshire PA9 1AF Tel: 01505 705 635 www.svh.co.uk	8 beds, home care, day care, bereavement service,
Greater Glasgow & Clyde	Dept of Palliative Care , Beatson West of Scotland Cancer Centre, Gartnavel General Hospital, 1053 Great Western Road, Glasgow, G12 OYN, 0141 301 7042	Hospital Support Team, deals with non-cancer too.
Greater Glasgow & Clyde	Glasgow Royal Infirmary Palliative Care Team, 84 Castle Street, Glasgow, G4 0SF, Tel 0141 211 4541	Hospital Support Team, NE Glasgow, G4, G21 - G23, G31- G34, G40, G62 - G64
Greater Glasgow & Clyde	Palliative Care Practice Development Social Work Building, Lightburn Hospital, 966 Carntyne Road, Glasgow, G32 6ND Tel 0141 211 1597	Hospital Support Team,
Greater Glasgow & Clyde	Palliative Care Clinical Nurse Specialist Vale of Leven Hospital, Alexandria Dumbarton, G83 0AU Tel 01389 817338	Home Care Out Patients, Dumbarton, Helensburgh, Balloch, Alexandria, Craigendoran, Kilcreggan, Garelochhead,

Greater Glasgow & Clyde	Palliative Care Team, Royal Alexandra Hospital Corsebar Road Paisley Renfrewshire PA2 9PN Tel 0141 314 6114	Inpatients at RAH
Greater Glasgow & Clyde	Palliative Care Team Southern General Hospital 1345 Govan Road Glasgow Lanarkshire G51 4TF Tel 0141 201 1266	Inpatients at SGH
Highland	Highland Hospice, Ness House 1 Bishops Rd, Inverness, IV3 5SB Tel: 01463 243132 www.highlandhospice.org	10 beds, home care, day care, bereavement service,
Highland	Macmillan Nursing Service Migdale Hospital Bonar Bridge Sutherland IV24 3AP Tel 01863 766790	Bereavement Service Home Care Inpatient Unit, North & West Sutherland & Kyle of Sutherland
Highland	Cowal Hospice, 360 Argyll Street. Dunoon, Argyll, PA23 7RL Tel 01369 708309	GP run, 4 bed unit, Day Hospice, Hospital Support Nurse
Highland	Cowal Hospice, MacMillan Service Health Centre, High Street, Isle Of Bute, PA20 9JL Tel 07769886505	Home Care, Cowal and Bute
Highland	Dingwall Macmillan Nurse Specialists Larachan House 9 Docharty Road Dingwall Ross and Cromarty IV15 9UG Tel 01349 865870	Home Care, Bereavement Service, Ullapool & Gairloch and Mid Highland - Stratpeffer to Tain inclusive
Highland	Fort William MacMillan Service, Belford Hospital Belford Road, Fort William, PH33 6BS Tel 01397 702481 Ext 4281	Home Care, Hospital Support Nurse
Highland	Golspie, MacMillan Nurse, Lawson Memorial Hospital, Golspie, East Sutherland, KW10 6SS, Tel 01408 664063	Home care, Hospital Support Nurse, East Sutherland, KW8 to KW10, IV25, IV24, IV27
Highland	Inverness Palliative Care Advisory Service, 5th Floor, Raigmore Hospital, Old Perth Road, Inverness IV2 3UJ, Tel 01463 704000 ext: 5405/5546	Hospital support Team
Highland	Inverness, MacMillan Nursing Service,, Netley Centre, Bishop's Road, Inverness, IV3 5SB Tel 01463 233659	Home Care, Bereavement Service, Inverness-shire, Ross-shire, Nairn, Badenoch, Strathspey, IV, PH
Highland	Islay Macmillan Nurse Specialist, Islay Hospital, Bowmore, Isle of Islay, PA43 7JD, Tel 01496 301021	Home care, Hospital Support Team, Isle of Islay & Isle of Jura
Highland	Lochgilphead Macmillan Service, Mid Argyll Community Hospital & Integrated Care Centre, Blairbuie Road, Lochgilphead, Argyll, PA31 8JZ, Tel 01546 462225	Home care, Hospital Support Team, Bereavement Service
Highland	Palliative Care Service Campbeltown Hospital, Ralston Road, Campbeltown, PA28 6LE Tel 01586 555822	Beds, Home care, Hospital Support Team, Bereavement Service.
Highland	The Oban Hospice, Lorn & Island District General Hospital Glengallan Road Oban Argyll PA34 4HH, Tel 01631 788928 www.obanhospice.org.uk	Note: At present this is a 1 day per week day hospice

Lanarkshire	Airdrie Palliative Care/Oncology Service , Monklands Hospital, Monks court Avenue, Airdrie , ML6 0JS, Tel 01236 748748 ext 2156 bleep 543	Bereavement Service, Carers Service, Lanarkshire
Lanarkshire	East Kilbride Hospital Macmillan Service , Hairmyres Hospital, Eaglesham Road, East Kilbride, Lanarkshire, G75 8RG, Tel 01355 584656	Hospital Support Team, Lanarkshire
Lanarkshire	Kilbryde Hospice Red Deer Centre Alberta Avenue East Kilbride Lanarkshire G75 8NH Tel 01698 717260	Day Care, Bereavement Service, South Lanarkshire
Lanarkshire	Lanarkshire Macmillan Service , Calder Unit, Udston Hospital, Burnbank, Hamilton, ML3 9LA, Tel 01698 723278	Home care, Bereavement Service
Lanarkshire	Motherwell Dalziel Day Unit , Strathclyde Hospital, Airbles Road, Motherwell, ML1 3BW, Tel 01698 245026	Day Care, Hospital Support Team Bereavement Service, Drop-in Information Service, Out Patients; Lanarkshire, ML1, to, ML12, & G74, G75
Lanarkshire	St Andrews Hospice , Henderson Street, Airdrie, Lanarkshire, ML6 6DJ Tel: 01236 766951 www.st-andrews-hospice.com	32 beds, home care, day care, bereavement service,
Lanarkshire	Wishaw , Palliative Care Team, Wishaw General Hospital, Netherton Street, Wishaw, ML2 0DP, Tel 01698 366053	Hospital Support Team, Out Patients, South Lanarkshire
Lothian	Edinburgh Marie Curie Hospice , Frogston Road West, Edinburgh, EH10 7DR, Tel: 0131 470 2201 http://hospiceedinburgh.mariecurie.org.uk/	27 beds, home care, day care, bereavement service,
Lothian	St Columba's Hospice , Challenger Lodge, 15 Boswall Road, Edinburgh EH5 3RW, Tel: 0131 551 1381 www.stcolumbushospice.org.uk	30 beds, home care, day care, bereavement service,
Lothian	Edinburgh Palliative Care Service , c/o Royal Infirmary of Edinburgh, 51 Little France Crescent, Old Dalkeith Road, EH16 4SA, Tel 0131 242 1990	Hospital Support Team, Edinburgh and Lothians
Lothian	Palliative Care Team Directorate of Clinical Oncology Western General Hospital Edinburgh Midlothian EH4 2XU Tel 0131 537 3094	Breathlessness Clinic Out Patient, South East Scotland, EH, FK, KY
Lothian	Haddington, Macmillan Nurses , 1st Floor, East Fortune House Roodlands Hospital Haddington East Lothian EH41 3PF, Tel 0131 536 8332	Home Care, Bereavement Service, East Lothian
Lothian	West Lothian Specialist Palliative Care Service , Macmillan Centre, St John's Hospital, Howden, Livingston, EH54 6PP, Tel: 01506 523531(Macmillan Centre) Tel: 01506 522010 (Hospital Support Team) Home Care: 01506 414586	Home Care, Day Care, Hospital Support Team, Bereavement Service, West Lothian, EH47, EH48, EH49, EH51, EH52, EH54

Orkney	Orkney Macmillan House , Kirkwall, Balfour Hospital, New Scapa Road, Kirkwall, Orkney, KW15 1BH, Tel 01856 888249	Home Care, Home Hospice, Day Care, Hospital Support Team, Bereavement Service Orkney Isles, KW15, KW16, KW17
Shetland	Lerwick Macmillan Nursing Service , Gilbert Bain Hospital, South Road, Lerwick, Shetland, ZE1 0TB, Tel 01595 743347	Home Care, Hospital Support Nurse, Shetland
Tayside	Brechin, Macmillan Centre , Stracathro Hospital, Brechin, Angus, DD9 7QA Tel 01356 665014	30 Beds, Home Care and Day Care, Angus, The Mearns, DD6, DD7, DD8
Tayside	Dundee Macmillan Hospital Palliative Care Team , Ninewells Hospital and Medical School, Ninewells, Dundee, DD1 9SY, Tel 01382 632478	Hospital Support Team Tayside & North Fife
Tayside	Perth, Palliative Services , Cornhill Macmillan Centre Perth Royal Infirmary Jeanfield Road Perth Perthshire PH1 1NX, Tel 01738 413000	Hospital Support Team, Perth, Kinross, PH1, to PH18, KY13, KY14, DD2, FK14 & FK15
Tayside	Roxburghe House & Macmillan Day-Care Centre , Royal Victoria Hospital, Jedburgh Rd, Dundee, DD2 1SP Tel: (01382) 423000, 01382 423132	24 Beds, Day care,, Home care support team, Tayside & North East Fife, DD, PH
Tayside	Strathmore Hospice - Lippen Care, Whitehills Centre, Station Road, Forfar, Angus, DD8 3DY, Tel 01307 475256	Beds: 4 + Bereavement Service, Forfar, Kirriemuir & surrounding areas, DD8
Western Isles	Bethesda Hospice , Springfield Road, Stornoway, Isle of Lewis, HS1 2PS Tel: 01851 706222 www.bethesdahospice.co.uk	4 beds, home care, day care, bereavement service,
Western Isles	Benbecula Macmillan Home Care Sister , 25 Winfield Way, Balivanich, Benbecula , Western Isles, HS7 5LH, Tel 01870 603010	Home Care, Hospital Support Nurse, Bereavement Service, Islands of Berneray, North & South Uist, Grimsay, Benbecula, Eriskay, Barra, Vatersay HS6, HS7, HS8, HS9
Western Isles	Stornoway Macmillan Service , Western Isles Hospital, Macaulay road Stornoway, Lewis, HS1 2AF, Tel 01851 704704 ext 2479	Home Care, Hospital Support Nurse, Bereavement Service, Lewis, Harris, HS1, HS2, HS3, HS4, HS5

Appendix C Respite Care Services

Your own **Local Authority** should have a list of respite care resources and services available to you. In some cases you might need to request a “Carer’s Assessment” in order to fully access the service. Your local authority’s main office contact details can be found at www.mndscotland.org.uk/wp-content/uploads/2011/09/Local-Councils-2009.pdf

The **Care Information Scotland** service, aimed at older people, can be contacted by telephone on 08456 001 001. Their website has a section specifically aimed at those who are new to seeking information on care services and explains issues like, how to get an assessment of your care needs, care at home and support for carers amongst others. Their website is at www.careinfoscotland.co.uk/home.aspx

Shared Care Scotland is an organisation with charitable status which promotes and supports the development of short break services for carers. Their telephone number is 01383 622 462 and their website is at www.sharedcarescotland.org.uk

Leuchie House, formerly run by the MS Society, is now an independent charity offering short breaks to people with a long term physical condition. Check availability and costs by phoning 01620 892 864 or emailing enquiries@leuchiehouse.org.uk

The Charity “**Crossroads**” operates on a local group basis to offer respite care services at home to allow the principal carer time to themselves. The organisation’s website is at www.crossroads-scotland.co.uk

Crossroads Services at mid 2011 were provided by the following groups:

Aberdeen	Kincardine & Deeside
Annandale & Eskdale	Largs & District
Badenoch & Strathspey	Lewis
Blantyre	Lochaber
Caithness	Mid & Upper Nithsdale
Clackmannan	Midlothian & East Lothian
Cobhair Bharraigh	Moray
Cowal & Bute	Nairn & District
Dalriada & The Isles	Newton Stewart
Dumfries & Lower Nithsdale	North Argyll
Dundee	Orkney
Dunfermline	Perth & Kinross
East Banff & Buchan	Ross & Cromarty
East Dunbartonshire	Shetland
East Sutherland	Skye & Lochalsh
Edinburgh	South Ayrshire
Falkirk	Stewartry
Fife Central	Stirling
Glasgow East	Stranraer
Glasgow West & South	West Lothian
Harris	West Stirlingshire
Inverness	

Other respite services may be available in your local area. Generally you will find this kind of local service advertised in your local Citizens Advice Office, local hospital notice boards and similar places.

APPENDIX D MND Related Books and DVDs

Each of the following can be borrowed at no charge from the MND Scotland library.

Books

If Only I'd Known That: Living With Ill-Health, Injury Or Disability. Royal Association For Disability And Rehabilitation (Great Britain) 9th Edition London : RADAR, 2011.

Motor neurone disease: the 'at your fingertips' guide / Stuart Neilson, Frank Clifford Rose. London : Class, 2003.

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families – Hiroshi Mitsumoto and Theodore L. Munsat, editors, 2001.

Motor Neuron Disease : A Practical Manual Kevin Talbot, Martin R. Turner, Rachael Marsden, and Rachel Botell. Oxford : Oxford University Press, 2010.

Motor Neurone Disease : A Family Affair /Dr David Oliver.3rd edition London : Sheldon Press, 2011.

A Booklet for Young People – Amyotrophic Lateral Sclerosis Society of Canada, 1998.

Grief In Young Children: A Handbook For Adults, Atle Dyregrov ; [Foreword By William Yule]. London, Philadelphia : Jessica Kingsley Publishers, 2008.

Talking About Death: A Dialogue Between Parent and Child – Eric Grollman, Beacon Press 1990

Coping With Your Partner's Death: Your Bereavement Guide. Geoff Billings, London Sheldon Press, 2008.

Motor Neurone Disease. Coping with grief: strategies for people living with MND. Mary Ward, MND Association of Victoria Inc, 2003

Easy to Swallow, Easy to Chew Cookbook, Donna L. Weihofen – John Wiley, 2002.

End of life care. The facts. A booklet for people in the final stages of life, and their carers. Debbie Coats [Foreword by Esther Rantzen], Marie Curie Cancer Care and Cancerbackup, 2007.

My Donkey Body: Living With A Body That No Longer Obeys You! Michael Wenham. Oxford : Monarch Books, 2008.(The story of a church minister's struggle with motor neurone or Lou Gehrig's Disease, told with courage, humour and faith)

Palliative Care In Neurological Disease : A Team Approach Edited By Judy Byrne [Et Al.]. Oxford : Radcliffe, C2009

What If It's Not Alzheimer's? A Caregiver's Guide To Dementia. Edited by Lisa Radin & Gary Radin, foreword by John Trojanowski. Amherst, N.Y. : Prometheus, 2008

Coping With Dementia : A Practical Handbook For Carers revised and updated by Kate Fearnley. Edinburgh : NHS Health Scotland, 2009. (See below for accompanying DVD.)

DVDs and Videos

The Man who Learned to Fall, Beitel/Lazar Productions Inc,2004 The story of an MND Journey- DVD and Video

Tuesdays with Morrie – Based on the book by Mitch Albom, Odyssey 2000 DVD and Video

Breath Of Life: Mechanical Ventilation In Neuromuscular Disease: medical education from the Muscular Dystrophy Association. (USA)

Gastrostomy Feeding, St Mark's Hospital and Academic Institute, London, DVD

Dysphagia, Experiences Of People With Swallowing Difficulties. Northern Legacy CIC Productions, 2009

ALS And Respiratory Failure: Diagnosis, Treatment And Home Ventilation, Drs MJ Hecht & M Winterholler, the German Neuromuscular Society, 2007

State of the Art Communication for People with ALS, Birger Berger Jepsen Synvision, 2007.

Coping With Dementia : A Practical DVD For Carers. NHS Health Scotland 2010

This DVD is for people caring for someone in the middle to late stages of dementia. It helps to understand dementia and learn from other carers' experiences. It also provides practical suggestions about caring.

MND Scotland Patient Information File

MND Scotland provides a free information file to every patient diagnosed with MND and in contact with their MND Scotland Care Team Member. The folder comes with factsheets 1, 23, 31 and 32 (underlined below) already inserted; the other available factsheets are listed in the table and all can be downloaded from our website at www.mndscotland.org.uk/information. For those without internet access staff at MND Scotland can post out pre-printed factsheets on request.

1 Introductory		8 Research, Drugs and Trials	
<u>1</u>	<u>What is MND?</u>	26	Current Research
1B	What is MND More Detailed	18	Clinical Trials
2	Inherited MND	16	Stem Cells
2 Coping with MND		28	Complementary Therapies
<u>23</u>	<u>Tools to Help You</u>	10	Creatine
27	Coping with MND	11	Vitamins and MND
29	Telling Children About MND		Genetics
3 Information and Support		9 Genetics	
<u>32</u>	<u>MND Scotland</u>	3	Introducing Genetics
<u>31</u>	<u>Sources of Support</u>	3B	Disease Inheritance
20	Library and Information	10 Breathing and Bulbar Symptoms	
43	Useful Organisations	34	Adapting to Swallowing Problems
47	Recommended Reading	6	Feeding Tubes
4 Caring and Carers		36	Oral Health
42	Being a Carer	35	Breathing Matters
15A	Care at Home	40	Ventilation in MND
15	Palliative Care	30	Communication Strategies
5 Money Issues		11 Motoring & Travel	
38	Financial and Legal Issues	9	Travelling and Holidays
4	Benefits in Brief	12	Travel Insurance
46	Bereavement Benefits	17	Motoring and MND
49	Managing Your Money	37	Long Distance Travel
6 Managing Symptoms		12 Death, Dying and Bereavement	
33	Managing MND	8	Care Planning and End of Life Issues
39	Lithium	14	Leaving a Legacy
22	Riluzole	24	Powers of Attorney
7 Physical Disability		25	Guardianship and Intervention Orders
5A	Assistive Equipment	44	Advance Directives
5B	Maintaining Mobility	48	Medical Bequests
5C	Getting the Best From Physiotherapy	45	After a Bereavement
5D	Aids to Maintain Mobility	13	Coping after Bereavement
19	Sex and Sexuality (in development)	7	Bereavement and Children
21	Specialist Clothing		



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*MND Scotland is the only charity funding research and providing care and information
for those affected by MND in Scotland*