allowing people to interact with services on a **flexible basis**

THERAPISTS IN MS

delivering the long-term solutions

Contributors

This publication has been written by a project group, formed as part of the Therapists in MS initiative.

Heidi Bedford
Senior I Physiotherapist
Royal Hospital for Neuro-Disability, Putney

Rosalind Edwards
MS Specialist Occupational Therapist
West Berkshire Council

Michelle Ennis
MS Specialist Occupational Therapist
The Walton Centre for Neurology and Neurosurgery, Liverpool

Clare Laing
Specialist Speech and Language Therapist
Horizons Rehabilitation Centre, Aberdeen

Jane Nicklin
Deputy Director of Education / Lead AHP
Essex Workforce Development Confederation

Alison Nock
Senior Occupational Therapist
MS Service, Poole Hospital NHS Trust

Annette Pauli
Clinical Specialist Physiotherapist in Neurology
University Hospital of Wales, Cardiff

Nicola Russell
Director of Services
Multiple Sclerosis Trust

Helen Sandell
Independent Occupational Therapist

Catherine Sykes
Deputy Head of Occupational Therapy Services
University Hospital, Birmingham

Jenny Thain
MS Specialist Physiotherapist
The Walton Centre for Neurology and Neurosurgery, Liverpool

Catherine Thornley
Education Officer
Multiple Sclerosis Trust

Further information about this group can be found at www.mstrust.org.uk/therapistsinms

The document was reviewed by the following experts and we are very grateful for their contributions.

Dr Mike Boggild
Lead Clinician
Department of Health Risk-sharing Scheme
The Walton Centre for Neurology and Neurosurgery, Liverpool

Marilyn Ekers
Service User, External Reference Group
National Service Framework for Long-term Conditions

Professor Pam Enderby
Chair of Community Rehabilitation
University of Sheffield

Philippa Ford MCSP
Policy Officer for Wales
Chartered Society of Physiotherapy

Dr Jenny Freeman
Reader in Physiotherapy and Rehabilitation/Honorary Lecturer
Plymouth University
Institute of Neurology, London

Jill French
Practice Development Physiotherapist
Greater Glasgow NHS (Primary Care Division)

Joanne Graham
Specialist Speech and Language Therapist
Chesterfield Royal Hospital NHS Foundation Trust

(On behalf of the Royal College of Speech and Language Therapists)

Jacqui Lunday
Allied Health Professions Officer
Scottish Executive Health Department

Karen Middleton
Health Professions Adviser
Department of Health

Sarah Rollinson
Senior Strategic Planning Manager
Hammersmith Hospitals NHS Trust

Julie Rigby
Consultant Therapist
Community Neuro-Rehabilitation Team, Salford and Trafford

Julia Skelton
Head of Professional Practice
College of Occupational Therapists

Barbara Stuttle
Director of Primary Care and Modernisation
Thurrock PCT

Julia Williamson
Team Leader Neuro-Physiotherapy
Regional Neurosciences Centre, Newcastle upon Tyne

(On behalf of the Association of Chartered Physiotherapists Interested in Neurology)

Dr Carolyn Young
Consultant Neurologist and Honorary Senior Lecturer in Neurology
The Walton Centre for Neurology and Neurosurgery, Liverpool

Contents

Foreword 4

Executive summary 5

Introduction 6

Overview of MS 7

The role of therapists in the management of MS 9

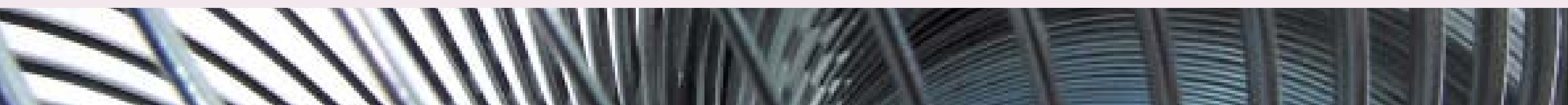
Specialist therapists 11

Delivering the quality requirements of the National Service Framework for Long-term Conditions: 14

- **Quality Requirement 1:** A person-centred service 14
- **Quality Requirement 2:** Early recognition, prompt diagnosis and treatment 16
- **Quality Requirement 3:** Emergency and acute management 18
- **Quality Requirement 4:** Early and specialist rehabilitation 20
- **Quality Requirement 5:** Community rehabilitation and support 22
- **Quality Requirement 6:** Vocational rehabilitation 24
- **Quality Requirement 7:** Providing equipment and accommodation 26
- **Quality Requirement 8:** Providing personal care and support 28
- **Quality Requirement 9:** Palliative care 30
- **Quality Requirement 10:** Supporting families and carers 32
- **Quality Requirement 11:** Caring for people with neurological conditions in hospital or other health and social care settings 34

Appendices 1 – 3 36

References 38



Foreword

Since devolution, the NHS operates differently in the four countries of the United Kingdom. In writing this document it was decided to use the quality requirements of the National Service Framework (NSF) for Long-term Conditions[1] as the framework for demonstrating the value of MS specialist therapy interventions.

It is recognised that so far, this NSF has only been adopted in England but the management of long-term conditions is also being developed in Scotland, Wales and Northern Ireland. In particular the principles laid out in the NSF for Long-term Conditions feature in Delivering for Health,[2] NHS Scotland, Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century,[3] NHS Wales, and Caring for People Beyond Tomorrow,[4] DHSSPS Northern Ireland. In addition, in Wales there is a specific review of neurological services due to publish its recommendations in 2006.

The NHS will always face financial pressures but using the broad principles of inter-disciplinary* working established in the NSF, aligned with increasing access to MS specialist therapists, can improve quality of life for people with MS and maximise the resources committed by the NHS.

We hope that this document will be of value to all commissioners of MS services and would welcome any relevant feedback.

Jane Nicklin

Helen Sandell

Co-Chairs of Therapists in MS
March 2006

*Inter-disciplinary Team = A team of individuals from different professional disciplines who work together in an integrated way and across health and social care settings where required, to deliver a person-centred service.

Executive Summary

KEY MESSAGES

1. Approximately 85,000 people have MS across the UK, and it remains the commonest cause of neurological disability in young adults. No specific register of people with MS exists, thus all numbers are estimates. For example the NICE MS Management Guidelines estimate that in England and Wales between 52,000 – 62,000 people have MS.[5,6]

2. MS is one of the most complex and variable conditions, and thus presents huge challenges to the health and social care systems, and to the staff who work within these areas.[7]

3. Currently, there is a shortage of MS specialist therapists and an inequity of service provision. Increasing the number of specialist therapists would allow a systematic inter-disciplinary approach to the care of people with MS. It would facilitate the management of patient discharge from hospital, thereby reducing length of stay as an inpatient and would streamline patient admission. It would also avoid unnecessary follow-ups for people with MS and ensure that when follow-up appointments are necessary, they take place in the appropriate care setting.[8-10]

4. Specialised MS services, as exemplified in tertiary referral centres and expanded for the implementation of the Department of Health Risk-sharing Scheme supported by all four UK health departments (see appendix 1), have shown real benefit for the management of MS, both from the patient perspective and for the NHS. [9,11]

5. Specialist therapists can help people with MS to remain in work, improve quality of life and prevent problems, as well as enabling the NHS and social care services to achieve their targets. Specialist therapists deliver anticipatory, proactive treatment and management rather than reactive care. They also encourage adoption of the public health agenda by promoting healthy living.[1,12-19]

6. Direct referrals to therapists can expedite care and the effective use of resources. Future commissioning of MS services should facilitate self-referral to specialists as exemplified in the White Paper; Our Health, Our Care, Our Say: a New Direction for Community Services.[19]

7. Specialist therapists aligned to the multi-disciplinary team are pivotal to the implementation of the NICE MS Management Guidelines and the NSF for Long-term Conditions as shown in detail in this document. In addition, as case managers, they operate in line with the Government's new model for the management of long-term conditions.[1,5,14, 20, 21]

8. Therapists bridge the gap between health and social care services - a key element in government strategy for the future management of long-term conditions, such as MS.[14,19-21]

PROPOSALS

1. Commissioners should work with service users and specialist therapists to develop service models providing users with access to specialist therapists in community, hospital and multi-agency settings. An expansion in the number of suitably qualified therapists will be required to achieve such services.

2. All inter-disciplinary teams should have specialist therapy input.

3. Models of service delivery should fit the local need but the 'hub and spoke' model developed for cancer services fits well for MS. The Department of Health Risk-sharing Scheme has initiated specialist MS centres across the UK and development of MS services should be undertaken in conjunction with these centres.[19,22,23]

4. Specialist therapists should be used to provide an effective bridge between health and social care services.

5. Research should be funded to further develop the evidence base for specialist therapy interventions.

6. Studies should be commissioned for local populations that model these proposals.

Introduction

The launch of the NICE MS Management Guidelines[5] in November 2003 and the NSF for Long-term Conditions[1] in March 2005 has provided a real impetus for change in the management of multiple sclerosis (MS). Both of these publications are aligned to the Government's model for the management of long-term conditions and recognise that people living with a long-term condition should be at the centre of the management process.

MS remains the commonest cause of neurological disability amongst young adults and its variable and complex course makes it one of the greatest challenges for the NHS and social care services.[7]

Therapists, both specialist and generalist, play a pivotal role in improving the quality of life of people affected by MS and this publication sets their interventions in context. For the scope of the publication, the term "therapist" covers occupational therapy, physiotherapy and speech and language therapy, although it is recognised that other allied health professionals (see appendix 2) also have a role in the management of MS.

This publication is aimed at all commissioners of MS services, including GPs. It will also benefit providers of services, allied health professionals and their managers. It specifically highlights the role of specialist therapists in the implementation of the NICE MS Management Guidelines[5] and the NSF for Long-term Conditions.[1] It also highlights their role in the education of non-specialist health professionals, and the part they can play in inter-disciplinary working.

The quality requirements of the NSF have been used as the structure for the document although it is recognised that the NSF only applies to England. However, the management of long-term conditions is also being developed in Scotland, Wales and Northern Ireland and the principles of the NSF feature in policy papers in these countries, specifically Delivering for Health,[2] NHS Scotland, and Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century,[3] NHS Wales. In Northern Ireland the suspension of the Assembly has had an impact on policy development but a new primary care strategy was recently announced entitled Caring for People Beyond Tomorrow[4] which encapsulates the same principles.

As well as focusing on the quality requirements of the NSF, this publication explores the role of therapists in addressing other relevant targets for the NHS and social care. These include keeping people in work, reducing hospital admissions, developing partnership working, introducing personalised care plans, case management and providing access to rehabilitation at whatever point it is required.[1,8,19-21]

In some parts of the UK, people affected by MS have access to excellent specialised services, while in others they are less fortunate. Examples of evidence-based good practice are included and it is hoped that these provide a vision for commissioners and service providers of what is possible. The NSF has a ten-year implementation timeframe and the goal is to ensure that during this period, equal access to quality therapy services can become the norm for people affected by MS.

This publication has been produced by a steering group of therapists from across the UK, both specialist and generalist, and reviewed by external experts. It provides a challenge to commissioners in both health and social care settings in terms of maximising the role of therapy interventions and structuring services to best effect for people affected by MS, in order to maximise resources and to deliver the Government's key targets.

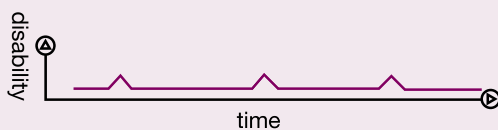
Overview of MS

85,000 people in the UK are estimated to have multiple sclerosis (MS). This long-term, chronic neurological disorder is sometimes benign, frequently remitting, but often progressive with gradually increasing disability. Between three and seven people per 100,000 are diagnosed with MS per year. In the UK, prevalence is approximately 100 – 120 per 100,000.[24] This figure is higher in Northern Ireland and Scotland, and especially in Shetland and Orkney, where the highest known prevalence of 200 per 100,000 has been recorded.[25,26]

MS is the most common condition of the central nervous system (CNS) affecting people between the age of 20 and 40. About twice as many women as men are affected. MS can be diagnosed in children as young as five and in people over 65, but this is unusual. MS can affect all aspects of a person's life and impact on the people around them. Having MS means living with uncertainty and adapting to changing situations.[6]

THERE ARE FOUR RECOGNISED TYPES OF MS[27]

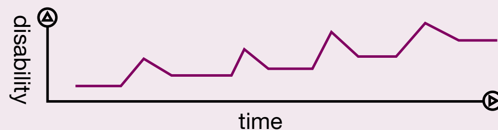
1. Benign



1. Benign

This type of MS is associated with very occasional relapses, with good recovery in between and minimal symptoms. Some neurologists estimate that more than 20% of people affected by MS have this benign form of the condition.

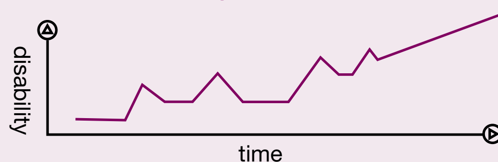
2. Relapsing/remitting



2. Relapsing/remitting

Initially, about two thirds of people have this form of MS. They experience relapses on average once or twice per year, with good or complete remission in between. However, there is a tendency for symptoms to worsen very gradually over time.

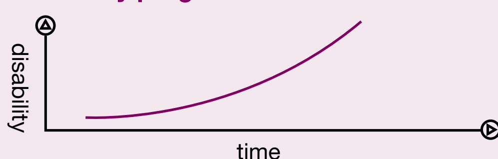
3. Secondary progressive



3. Secondary progressive

Many people who start off with R/R MS go on to develop a progressive form of the condition after a number of years. The severity and frequency of the relapses decreases, but disability slowly increases.

4. Primary progressive



4. Primary progressive

About 10% of people experience symptoms right from the start that become progressively worse over a period of years without remission.

Overview of MS

Symptoms

The damage caused by MS can occur anywhere in the CNS, and as a result, symptoms can be extremely diverse. In a survey of 226[5] individuals with MS undertaken in 2004, the recorded prevalence rates of common MS symptoms were:[28]

Symptom	Prevalence
Balance and dizziness	92%
Bladder problems	87%
Bowel problems	74%
Fatigue	96%
Loss of memory and concentration	87%
Loss of mobility	91%
Pain	81%
Sensory problems	88%
Sexual problems	70%
Spasticity	82%
Speech and swallowing problems	68%
Tremor	68%
Vision problems	82%

MS symptoms can present in many different combinations, with variable severity and they can fluctuate. No two people will experience precisely the same pattern of symptoms, so it is important to base treatment on the person involved, rather than a collection of symptoms.

No two people will experience precisely the same pattern of symptoms, so it is important to base treatment on the person involved.

Management

Current medical management falls into three broad categories namely:[29]

1. **Disease modification therapy**
2. **Relapse management**
3. **Symptom management**

Disease modification therapy may not alter current symptoms but is aimed at affecting the immune system, reducing inflammation and slowing down the process of demyelination in the CNS, leading to a reduction in frequency and severity of clinical relapses and slowing progression of disability.[30]

The mainstay of relapse management is steroid therapy, which can be administered either orally or intravenously, on an inpatient or outpatient basis or at home. Doses used are high but there is no accepted standard dosage.[5]

Symptom management is aimed at minimising symptoms and reducing their impact on the person with MS and their daily activities. Many symptoms interact with each other, so careful medical management is required. It is mainly in the area of symptom management that therapists have a major role to play, alongside any medical interventions, to enable people affected by MS to manage their condition and maintain their quality of life.[5]

The role of therapists in the management of MS

Therapists are involved in the management of people with MS, as well as their families and carers, at all stages of the disease course, from initial diagnosis through relapse management to palliative care.

Professor Alan Thompson from the National Hospital for Neurology and Neurosurgery, London suggests that:

> "any model of care for MS has to have both the breadth and expertise to address the wide range of problems and the flexibility to cope with the variability, unpredictability and changing pattern of need"[31]

Occupational therapists, physiotherapists and speech and language therapists have individual aims for any specific intervention, but they complement each other and in many cases, combined working delivers the most effective results for the individual with MS.[10,11,15,32]

Occupational therapy aims

Occupational therapists enable people to achieve health, well-being, independence and life satisfaction through participation in occupation. In this respect the term "occupation" describes the activities that an individual undertakes and which define his/her being and their self-esteem, autonomy and purpose for living.[33]

It is recognised that people affected by long-term, chronic, or progressive conditions, such as MS, may not be striving to achieve independence in all activities of everyday life. Rather, occupational therapists enable them to participate, at whatever level they are able, in those occupations that the person with MS considers to be most meaningful and relevant.

Occupational therapists utilise specialist skills to assist individuals with MS to achieve their aims, primarily through:

1. analysing an individual's lifestyle, activities and roles to identify areas of difficulty, and working with the individual to learn or re-learn ways in which activities can be successfully carried out, through specific treatment techniques.
2. adapting the activity itself, for example by advising on specialist equipment to assist in carrying it out, or learning a new technique.
3. modifying the environment in which an activity is carried out, for example by changing attitudes/the environment within the workplace, or designing housing adaptations to remove or minimise obstacles.
4. educating and advising individuals on alternative occupations or activities in the context of their difficulties.

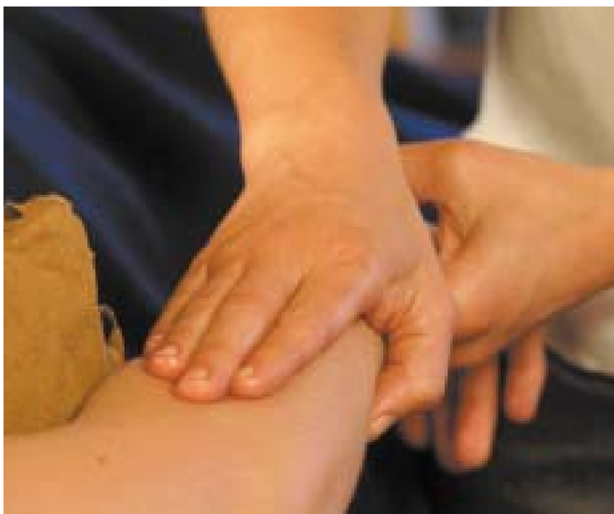
The role of therapists in the management of MS

Physiotherapy aims

Physiotherapy is a physical and educational treatment approach which is concerned with maximising mobility, movement and function. Physiotherapists are experts in human movement, from the way we move our backs and limbs, to the way in which we breathe. The primary aims of physiotherapy are to restore and maintain function, activity and independence and to prevent injury or illness through treatment, information and advice on healthy lifestyles.[34]

For people with chronic conditions such as MS, physiotherapists aim to:

1. improve and/or maintain muscle activity, balance, mobility, posture and joint range through retraining, specific treatment techniques, exercise and activities of daily living.
2. develop strategies with the individual to manage symptoms such as pain and spasticity.
3. assist the person in adapting to and maintaining their maximal safe and independent functional ability, engaging the person in self-management techniques.
4. encourage and motivate the person to maintain cardiovascular fitness and overall health and well-being through treatment techniques and education.



Speech and language therapy aims

People affected by MS can present with a variety of speech, language and swallowing symptoms.[35] The speech and language therapist will assess the pattern of communication and swallowing problems and, in consultation with the person affected by MS, determine the most effective way to manage these.

Through active treatment and support, speech and language therapy input helps people with MS by:

1. facilitating and maintaining speech or providing appropriate augmentative and alternative communication devices.
2. maintaining effective interaction and communication skills, enabling the individual to participate in conversation and decision-making processes.
3. assessing and managing swallowing difficulties that may change through the course of the condition, including advice on management of oral secretions and mouth care.
4. advising on posture and techniques to promote safe and effective swallowing and, where appropriate, involvement in decisions regarding the implementation of alternative feeding.

Specialist therapists

A person affected by MS will come into contact with therapists in a variety of settings, as therapists work across all health and social care settings within the NHS, in the private, independent and voluntary sectors, as well as in the residential and nursing home environment.

However only a minority of people with MS will currently come into contact with MS specialist therapists. There are approximately 100 such professionals working across the UK, despite the fact that evidence is growing to support the value of such posts.[9-11,32]

Growth in the number of MS specialist therapists runs in parallel with a growth in the number of MS specialist neurologists, and MS specialist nurses. This 'hub and spoke' model of care is one that has been well tested in the cancer field and is now starting to show real benefit for the NHS as a way of managing the uniquely challenging condition of MS.[1,22] Appendix 1 shows the MS specialist centres identified through the Department of Health Risk-sharing Scheme.

The benefits of specialist therapists

MS specialist therapists have a detailed, extensive knowledge and understanding of MS, in terms of its pathology, treatment options and functional implications. This concentrated and focused area of practice enables the specialist therapist to develop the core skills of their particular profession with specific reference to the care of people with MS. Expert knowledge is used in case management and the implementation of specialist clinical interventions. The experience gained by MS specialist therapists enables them to adopt a problem-solving approach that helps people with MS maximise their abilities and thus their quality of life.

Specialist therapists provide formal and informal education and support to non-specialists in order to enhance the care provided to the person with MS. They are key drivers in the development of new MS services, using their in-depth knowledge of the condition and its impact to shape resources in order to provide the optimum services for people with MS, within NHS and social care frameworks. Research is also a fundamental element of the specialist role, helping to develop the evidence base.

MS specialist therapists work collaboratively with other therapists, and members of the inter-disciplinary team, through the provision of evidence-based specialist care and comprehensive management of day-to-day difficulties. This approach helps the person with MS to achieve their highest possible quality of life, and is in line with the recommendations specified within the NICE MS Management Guidelines and the NSF for Long-term Conditions.[1,5]

In essence the provision of more specialist therapists would allow:

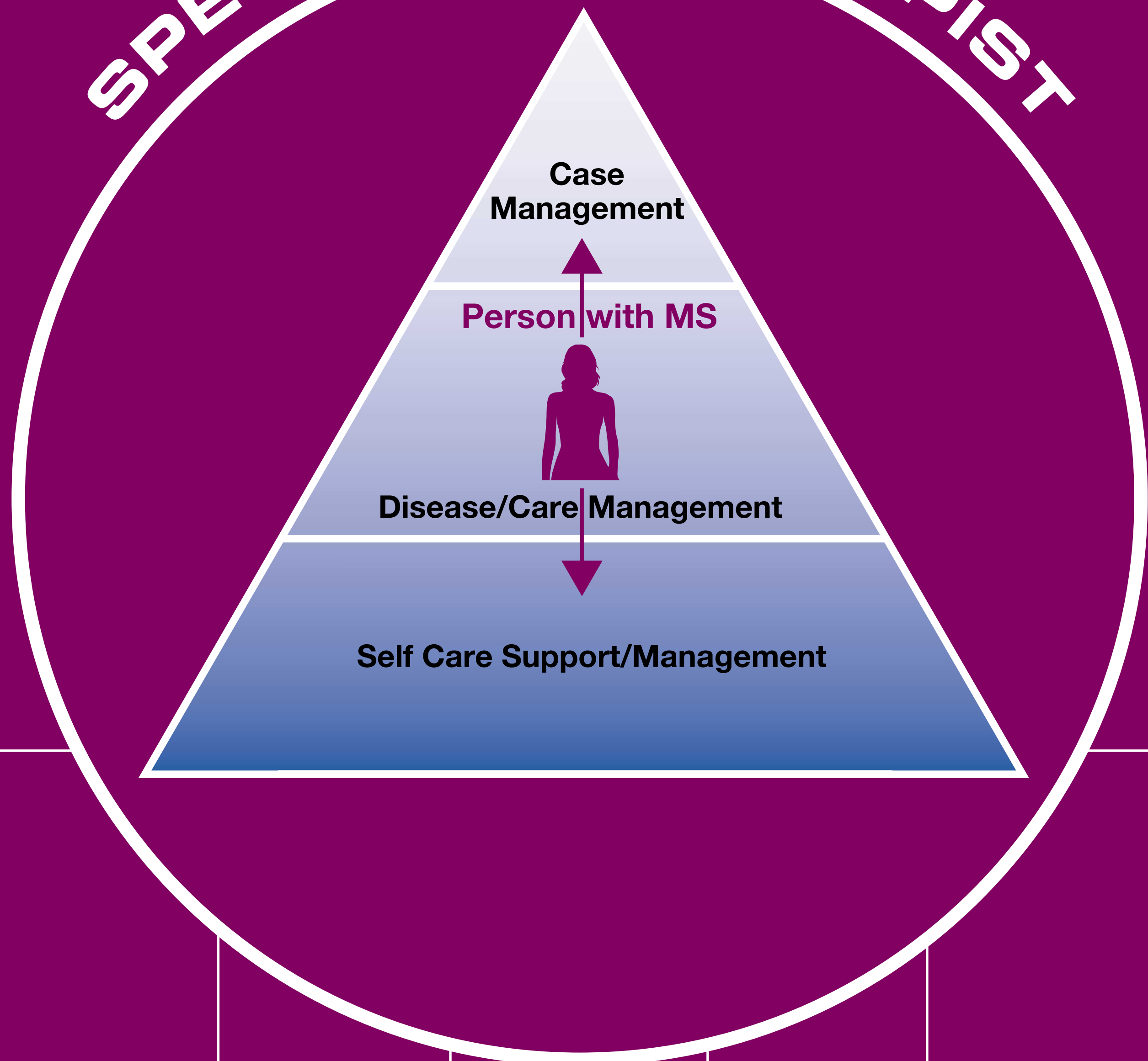
1. the effective delivery of case management, both directly, if appropriate, or indirectly, via identification of high intensity users of unplanned secondary healthcare.[20]
2. more effective management of admission and discharge from hospital, thereby minimising hospital admissions and reducing the length of stay.[8,10]
3. the use of specialist expertise to manage specific symptoms, including cognition, fatigue, pain, spasticity, speech and swallowing difficulties.[36-41]
4. the enablement of people with MS to self manage their condition.[42]
5. greater opportunities for people with MS to remain within the community and home care settings.[15,32,42,43]
6. access to individuals with specialist knowledge to work with commissioners in service re-design, and the provision of leadership for services.[14,32] (See appendix 3)

Specialist therapists

Specialist therapy competencies	Benefits of a specialist therapy service
In depth knowledge of MS across the disease spectrum	■ Prevention of admissions to hospital – by maintaining the individual in their home environment ■ Effective discharge planning from hospital ■ Effective case management ■ Proactive approach to MS management thereby reducing crisis situations and facilitating effective planning ■ Release (or freeing up) of consultant time ■ Improved patient and carer confidence/satisfaction
High level therapy skills and advanced clinical reasoning	■ Maintenance of the person's ability to remain in work ■ Maximisation of quality of life ■ Health promotion and exercise within the individual's limitations ■ Prevention of secondary complications ■ Implementation of the NICE MS Management Guidelines in all areas of symptom management, as part of an inter-disciplinary team[5]
Extensive clinical experience of treating different types of MS	■ Ability to bridge the gap between the consultant and other health and social care professionals ■ Provision of appropriate information to people affected by MS and other health and social care professionals ■ Cost-effective provision of MS services
Highly effective communication skills	■ Provision of information to people with MS, including breaking bad news and explaining loss and ways to manage loss ■ Education of other health and social care professionals ■ Effective communication across health, social care and voluntary sectors ■ Ability to bridge the gap between the consultant, the person with MS and other professionals
Networking skills and knowledge of national, regional and local facilities/staff	■ Service development ■ Care co-ordination ■ Appropriate and timely referral to other health and social care professionals ■ Effective, and more efficient usage of resources
A passion for MS management	■ Maximisation of the person's quality of life ■ Development of innovative models of MS management
Focused approach	■ Effective time management ■ Good team working ■ Ability to act as drivers for research to improve the evidence base
Foresight, gained through knowledge and experience about what may happen	■ Proactive management ■ Prevention of crises ■ Ability to act as a resource and provide support to other health and social care professionals

*The above table is not an exhaustive list. It has been developed in line with the Knowledge and Skills Framework,[12] the neurology competencies recently launched by Skills for Health,[13] and the competencies cited within the NSF for Long-term Conditions.[1] In addition to this the Professional Colleges are currently reviewing the specific professional competencies. [44-47]

SPECIALIST THERAPIST



Maximising functional abilities
•
Minimising disability

Maximising quality of life
•
Empowerment of the person with MS
•
Maintaining life roles

Prevention of complications
•
Prevention or delay of deterioration
•
Reduction of hospital admissions
•
Effective discharge planning allowing earlier discharge

Facilitation of cost effective care
•
Health promotion

Audit and research

Service development

Provision of education and information to people with MS and other health professionals
•
Effective communication and liaison
•
Supporting people with MS and their families and carers

Co-ordination of services
•
Case management

Triangle adapted from the Kaiser Permanente Model of Care [21]

QUALITY REQUIREMENT 1:
A person-centred service

Delivering the quality requirements of the NSF for Long-term Conditions

The case studies that follow illustrate particular aspects of delivering each quality requirement. They do not represent the whole management of the individual with MS and some examples demonstrate the current barriers to effective therapy interventions.

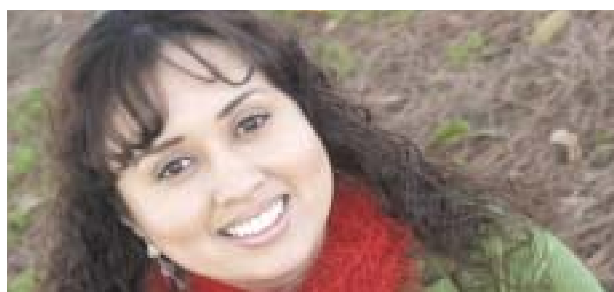
People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

THE ROLE OF THE THERAPIST [15,19,32,40,48-51]

- A client-centred approach, which enables self-management
- An holistic approach to assessment
- Effective communication between all members of the inter-disciplinary team, the individual and their family
- Functional assessment of an individual's home/work/life requirements
- Provision of appropriate, timely information and education for the person with MS, their family and/or carers
- Problem solving and planning, to provide choices and enable change for the individual
- Co-ordination of a seamless service across hospital, home, work and leisure environments
- Specialist treatment techniques
- Specialist knowledge of appropriate resources
- Provision of choice for the person affected by MS

Quote from a service user:

"I live my life in control of my disease rather than the disease controlling my life."



RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with a specialist knowledge of MS
- Integrated assessments leading to individualised, meaningful care plans
- Rapid self-referral by people with MS or via the GP
- Rapid referral amongst the inter-disciplinary team
- Therapy assessments available in the individual's varied environments, for example work or home
- Electronic integrated care records, client held notes, inter-disciplinary notes, or access to notes by all professionals
- Specialist therapists providing education for:
  - ward staff to ensure appropriate management during any hospital admission
  - primary care teams to ensure early identification of problems allowing timely rehabilitation at appropriate points in the disease course
  - people affected by MS and their carers, to support self-management and to ensure the provision of effective care, tailored to individual goals
- Availability of funding for equipment if required
- Provision of appropriate information for people with MS
- Availability of therapists who are trained to discuss the impact of MS with the person affected by MS and how the individual can manage 'loss'

CASE STUDY:

Never too late to learn - specialist MS service provides appropriate information to support patient choice

“I recently moved house and when registering with my new GP, he suggested a referral to a specialist MS service. I was sceptical and slightly aggrieved that he thought anyone could assist me in managing my MS - after all, I’ve been living with this condition without help for 20 years! My way of coping was to fight MS by keeping any difficulties to myself.

I reluctantly agreed to the referral and an appointment with the MS specialist team was arranged. At this appointment, the neurologist and MS specialist nurse were very helpful, answering the questions I had about the possible cause of MS and the genetic factors involved. I also spent time with the MS specialist therapists (an occupational therapist and physiotherapist), who wanted to discuss the practical impact of MS on my life. I found this quite difficult at first but realised that they had the knowledge and expertise required to offer me some practical solutions to consider. We agreed to work together on several issues; I needed to consider my general health and fitness, because I had allowed my weight to gradually increase as exercising had become more difficult. I learnt that the menopausal symptoms I had been experiencing could affect my MS symptoms, and we agreed to explore this further. I also admitted that since being made redundant, I had resigned myself to a life of daytime television and wasn’t sure what else the future could offer me.

At first I was unsure that I wanted to make changes to my life, but by setting plans with the therapists, I could see the potential benefits and agreed to further treatment sessions and referral on to other services.

The MS specialist therapists were confident that some of the problems that contributed to finishing work and weight gain were related to my MS symptoms. Through a combination of treatment sessions and medication these symptoms have much improved. A commitment is required from me to exercise regularly, which I found easier knowing that the exercise is safe, as well as beneficial. Hormone replacement therapy has vastly improved my mood and energy levels, which I had previously attributed to my MS, rather than the menopause. I also understand the importance of managing my fatigue effectively in conjunction with this treatment. We explored the regrets I have from stopping work prematurely, and the therapists helped me to consider alternative work options in the context of my MS.

Over time, I found that the MS specialist therapists were highly skilled in making me feel comfortable discussing my situation and eventually I also admitted to difficulties in several other aspects of my daily life. They advised that these particular problems would be most effectively worked on by my local community team and liaised with these professionals to ensure that this was followed up.

For 20 years I didn’t know that this type of MS service was available. I feel lucky to have moved to an area where I can access support. Everyone has listened and understood my needs, and the therapists have given me practical ways to manage my MS for the future.”

QUALITY REQUIREMENT 2: Early recognition, prompt diagnosis and treatment

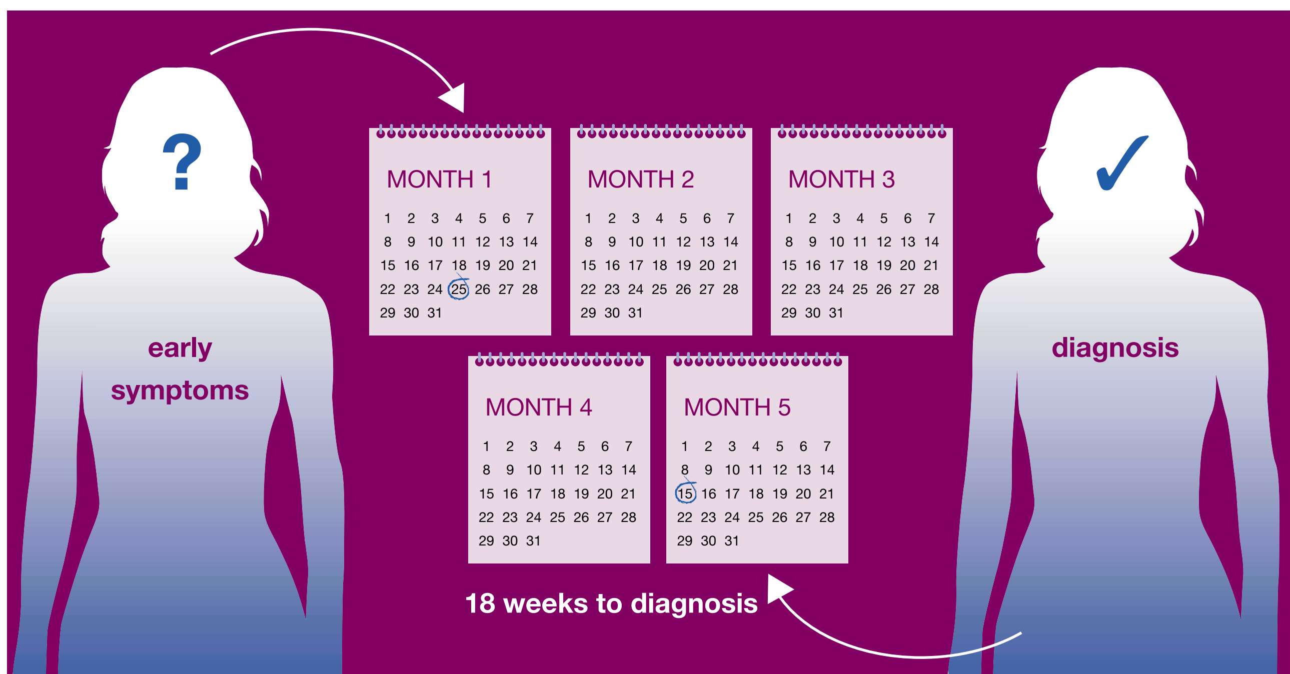
People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

THE ROLE OF THE THERAPIST[52-54]

- Recognition of symptoms prior to diagnosis and prompt referral for diagnosis
- Provision of appropriate information following diagnosis
- Support of the individual to manage the uncertainty of their diagnosis and the possible losses that this may bring
- Flexible options for holistic assessment at home or at an individual's workplace
- Flexible treatment options, tailored to the individual's situation
- Early therapy intervention (if appropriate)
- Provision of contact details for ongoing support

RECOMMENDATIONS FOR THERAPY SERVICE

- Rapid referral amongst the inter-disciplinary team
- Access to therapists with a specialist knowledge of MS - self-referral by people with MS
- Integrated assessments leading to meaningful care plans specific to individual needs
- Availability of speech therapy services early in the disease course to prevent crises
- Effective community therapy services, offering assessment and treatment
- Ensuring that appropriate information for people with MS is available
- Education of therapists to sensitively discuss the impact of MS with people affected by MS
- Appropriate review of individual needs as required
- Where appropriate, systems established for direct referral from therapist to neurologist to speed up the diagnostic process



CASE STUDY:

Amy shares her experience of being diagnosed with MS

"After suffering with back pain for months, I was finally persuaded by my husband to make an appointment to see a physiotherapist at my local hospital. I was very impressed with this first assessment. The physiotherapist was very thorough, asking lots of questions whilst checking my spine and testing my muscles and reflexes. Some questions seemed a little odd, such as "had I noticed anything unusual about my walking?" When I thought about this, I remembered that I had tripped several times during the previous few weeks. The physiotherapist told me that I needed to see a specialist team and in the first instance, referred me to a neurologist, via my GP. After a series of further investigations by the neurologist, I was told that I have MS.

Immediately after my diagnosis, the neurologist referred me to an inter-disciplinary MS team in the outpatient clinic. When I saw this specialist team (a nurse, occupational therapist, physiotherapist and speech and language therapist) I had a long list of questions about MS, which we discussed, and they provided information and reassurance. Because of my balance problems, I spent additional time with the MS specialist physiotherapist, agreeing a simple exercise and activity plan to improve my balance and also my general fitness.

My diagnosis knocked me for six, but gradually I have felt more confident to carry on with my life. It is reassuring to know I can contact the MS team again whenever I have any concerns in the future."

The physiotherapist at Amy's local hospital explained:

"Before advising Amy to see her GP, I telephoned the MS specialist physiotherapist to discuss the symptoms she was experiencing. This was really helpful because although I see a number of people who have MS, I have never been in the position of recognising symptoms prior to diagnosis."

"My diagnosis knocked me for six, but gradually I have felt more confident to carry on with my life."

QUALITY REQUIREMENT 3: Emergency and acute management

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

THE ROLE OF THE THERAPIST [9,10,21,32]

- Prevention of emergency situations and thereby admissions to hospital through effective community management
- Case management to ensure appropriate admission and co-ordination of the care package to reduce length of stay
- Effective early discharge planning
- Assessment of acute episodes and implementation of a treatment plan
- Key role in rapid response and relapse teams
- Management of any changes to an individual’s function including crisis management
- Risk assessment and management
- Prevention of secondary complications such as contractures and pressure sores

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with a specialist knowledge of MS
- Integrated assessments leading to meaningful care plans, specific to individual needs
- Clearly identified point of contact to enable rapid admission or management, during relapses and other acute episodes
- Appropriate treatment and advice for people with MS and their family/carers
- Specialist staff to educate ward staff to ensure the person with MS is managed appropriately during their hospital admission
- Effective early discharge planning
- Effective links between hospital and community services to ensure a seamless service

CASE STUDY:

Rapid response to an MS relapse

Mary was concerned about the sudden onset of new symptoms and rang her MS specialist nurse. Following discussion with Mary, the nurse made an immediate referral to the inter-disciplinary relapse clinic, with the specialist MS team. At this clinic a relapse was diagnosed and it was agreed that Mary would be admitted to hospital for a course of intravenous steroid treatment.

While the steroids were being administered, the specialist MS team initiated a range of therapy interventions. These included:

Occupational therapy interventions:

- Exploration of ways in which Mary could manage her everyday activities in the future
- Discussion of options for appropriate aids and equipment for her home
- Education on fatigue self-management
- Discussion of strategies for returning to work and driving

Physiotherapy interventions:

- Exercises to increase muscle strength and improve balance
- Education on how to maintain these exercises at home
- Therapy to improve the quality of Mary's walking

Speech and language therapy interventions:

- Assessment of Mary's speech and swallowing
- Advice on ways to modify the texture of her food, and safe swallowing techniques
- Introduction of strategies to improve precision of speech

The MS team also introduced Mary to a social worker during her admission, who would act as her local community contact following discharge from hospital. Information about appropriate local groups and resources were also provided.

Mary was offered an appointment with the specialist MS Team six weeks later to monitor the outcomes of her therapy, along with a medical review of the future management of her MS. Contact details were provided so that she could call them at any time for further support.

QUALITY REQUIREMENT 4:

Early and specialist rehabilitation

People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

THE ROLE OF THE THERAPIST[41,49,55-60]

- Identifying rehabilitation needs and rehabilitation potential
- Case management to facilitate transitions between the community and hospital/ specialist setting
- Specialist assessment leading to client-centred goals
- Individual and group treatment sessions
- Facilitation of integrated specialist therapy and inter-disciplinary working
- Education of people with MS and their families
- Problem-solving and planning to address continuing and changing needs
- Specialist knowledge to ensure appropriate and timely provision of equipment and aids
- Effective discharge planning, encompassing:
  - co-ordinated care packages
  - risk assessment and management
- Links to other disciplines such as dietitians, psychologists and social workers

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with a specialist knowledge of MS
- Effective inpatient and community rehabilitation services
- Systems in place to ensure a seamless transition between home, rehabilitation and return to the home environment
- Provision of equipment as required
- Rapid referral systems to other professional disciplines
- Joint documentation
- Goal-orientated treatment, where the individual's goals match the therapy goals
- Integrated care pathways
- Appropriate use of outcome measures
- Joint assessments and inter-disciplinary working
- Individual and group interventions
- Effective early discharge planning
- Review systems to monitor and maintain rehabilitation gains
- Effective education of primary care teams to ensure that problems are identified early and rehabilitation provided at appropriate points in the disease course

CASE STUDY:

The benefits of co-ordinated, inpatient specialist rehabilitation

"I have had MS for more than ten years now. Over the last six months I noticed that walking was becoming more difficult for me, I had greater trouble doing my intermittent self-catheterisation (ISC)* because my hands were shakier, and I seemed to find everything very tiring. I hadn't been going out as much in the evenings, and particularly missed my book group, because I was embarrassed about how slurred my speech was at the end of the day.

I felt that I needed something more than my local therapy so, after reading an article in an MS magazine, I asked my GP to refer me for rehabilitation.

Firstly, I was assessed by a senior team of therapists, doctor and nurse. They asked me what I wanted to achieve through rehab, and we agreed that I should have an inpatient admission of three weeks duration.

The first week included in-depth assessments. I had a "keyworker" assigned to me, who co-ordinated my stay. I was able to ask her any questions about my treatment. I had very intensive treatment from the team of therapists and nurses, often with two different therapists working together on something. I realised how great it was to have all the team in the same place at the same time, and it was clear to me that they were communicating about my needs and progress.

One of the great benefits of rehabilitation was that all the team members contributed in different ways towards solving the same problem. For example, the physiotherapist worked on strengthening my torso muscles, and the occupational therapist showed me that if I sat in a more supported position my arms wouldn't shake so much. The combination of both of these improvements meant that the nurses could help me practice my ISC more easily! The speech and language therapist taught me techniques to improve the precision of my speech, and this, coupled with attending some group sessions on fatigue, made me feel more confident about going back to my book group.

Knowing that I had three weeks made me focus on improving, without the distractions of home life and the effort of getting to and from outpatient treatment. I learnt many new things and met other people who had MS, but I wasn't too long away from my family. I'll continue to work on some of these ideas at home, as the team are in contact with my own therapists in the community."

"One of the great benefits of rehabilitation was that all the team members contributed in different ways towards solving the same problem."

*ISC is a self-management technique commonly used for people who experience incomplete emptying of the bladder in MS.

QUALITY REQUIREMENT 5: Community rehabilitation and support

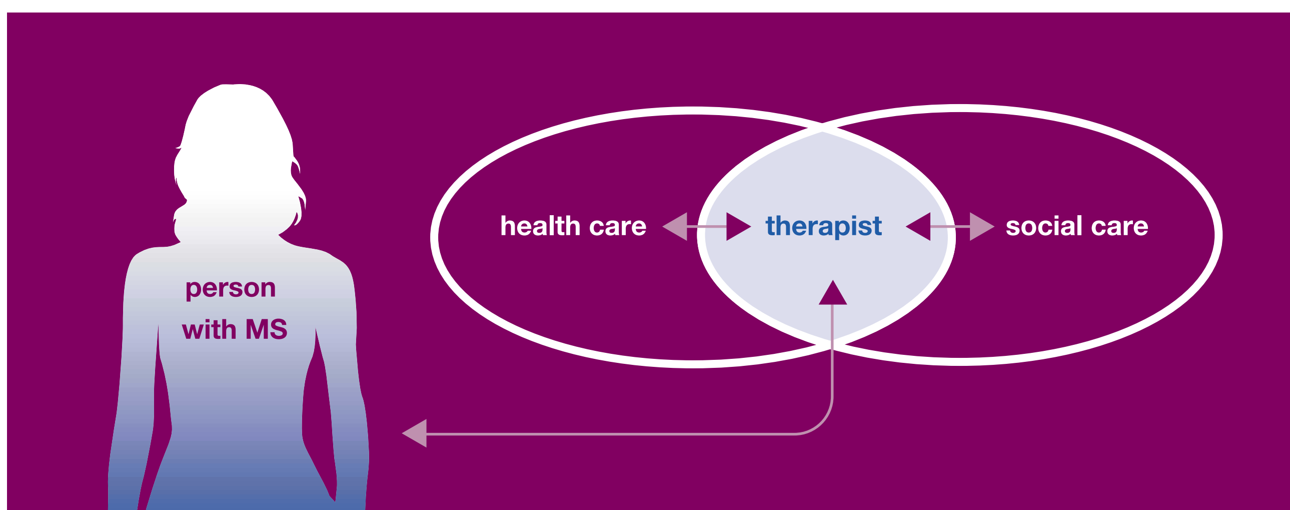
People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them live as they wish.

THE ROLE OF THE THERAPIST:[32,42,43,60-62]

- Identifying rehabilitation needs and rehabilitation potential
- Providing a flexible and accessible service when required
- Case management
- Holistic understanding of home, work and leisure environments
- Creative problem-solving to facilitate independence
- Initiation of self-management strategies and support to sustain them
- Information about appropriate community resources (leisure activities, support groups)
- Provision of specialist education groups:
  - health promotion
  - fatigue management
  - cognitive impairment groups
  - carer support groups

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with a specialist knowledge of MS
- Effective education of primary care teams to ensure that problems are identified early and rehabilitation provided at appropriate points and settings throughout the disease course
- Availability of specialist rehabilitation advice within the community environment
- Education of people affected by MS and their carers, to ensure strategies are in place to minimise the effects of fatigue and cognitive impairment and to maximise the individual's independence
- Self-referral system either direct by the person with MS or via the GP
- Effective referral systems within the inter-disciplinary team
- Knowledge of the available local resources, with good links across health and social care services



CASE STUDY:

A woman with MS describes the benefit she received from a community MS team

"Things had been going well since I was first diagnosed with MS. I had one or two relapses but recovered, and was able to continue working part-time and looking after my children. Recently I started feeling really tired after little effort and I found I couldn't keep up with the housework. By 3.15pm, when I had to collect my children, I could hardly face the five-minute walk to school and sometimes it was really hard to lift my right leg. I was also having trouble concentrating at work.

I thought I might need some physiotherapy, which I had previously had after a relapse. The local MS community team has a self-referral system, so I rang them for advice. The person I spoke to was really helpful and recommended an assessment at my home to agree the best way forward.

An occupational therapist, physiotherapist, and speech and language therapist, visited me at home. They explained that a joint assessment meant that I didn't have to repeat the same information over and over again. Their assessment was very detailed and included things I wouldn't have thought of mentioning, such as my speech, and I realised that I slur my words when tired. They also asked me to do some practical things like walking up and down my stairs, and tidying up some of the children's toys, so they could see how I was moving around. I was embarrassed to admit to them that I sometimes had accidents when I needed the loo in a hurry. I also told them that my husband gets really frustrated with me, because I'm so tired and I don't want to have sex any more.

At the end of the assessment they asked me if I would consider some rehabilitation. I was worried that they wanted me to go into hospital as I didn't want to leave my children, but they explained that they could actually work with me in my own home. They said I had a problem with 'fatigue' which was affecting everything from housework, to concentration at work and my speech. We talked about fatigue management and they gave me lots of great tips like working from home sometimes, and getting the children to help me more. They also referred me to other colleagues who could advise on my bladder and sex issues.

I was really happy because I felt that they'd listened to what I wanted. I now feel more in control, and I've got their number in case I need them again in the future."

"I was really happy because I felt that they'd listened to what I wanted."

QUALITY REQUIREMENT 6: Vocational rehabilitation

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities

THE ROLE OF THE THERAPIST[53, 63-65]

- Identifying rehabilitation needs and potential for improvement
- Vocational assessment of the individual in the work environment
- Specific treatment to address vocational goals
- Early intervention to keep people in work
- Education of:
  - people affected by MS, including provision of information regarding their rights and symptom management
  - employers and, where appropriate, work colleagues, Occupational Health Advisers and Disability Employment Advisers
- Provision of options for retraining/alternative employment, for example courses and skills development
- Advocacy on behalf of the person with MS
- Awareness of local community resources

RECOMMENDATIONS FOR THERAPY SERVICE

- Flexibility to offer early assessment and advice to maintain people in work
- Availability of inter-disciplinary therapy assessments in the work environment
- Education of employers to ensure their commitment to enable people with MS to remain in work
- Access to therapists with a specialist knowledge of MS
- Links to other services such as Access to Work schemes

CASE STUDY:

Vocational rehabilitation helps a solicitor to remain in the job he loves

John is a 38-year old solicitor, whose MS symptoms were causing him a great deal of stress due to their impact on his working role.

A joint assessment conducted by MS specialist therapists (physiotherapist and occupational therapist) and an orthoptist explored his employment concerns. Key difficulties were;

- fatigue, worsened by long working hours, carrying papers to and from court, and regular travel
- occasionally forgetting things communicated to him verbally
- using his computer due to his visual problems.

John expressed concern that he was not performing well enough at work, having always set high standards. He was anxious about losing his job, not only because he was the main financial provider to his family, but also because he had a passion for his work - it gave him satisfaction, confidence and challenged him. His concerns were affecting his sleep and his family relationships.

The MS specialist team and the Disability Employment Service worked together with John to evaluate his job and provide options for him to consider. Fatigue management education was a priority as fatigue greatly exacerbated his other symptoms. The MS specialist occupational therapist also advised on relaxation techniques to help improve his sleep and manage stress. Following a cognitive assessment by a work psychologist, the MS specialist occupational therapist began working with John on some appropriate cognitive rehabilitation strategies.

The MS team linked John into the Access to Work scheme. This scheme provided a number of practical solutions including; alternative means of transport to and from work, computer software packages to minimise the impact of his visual problems, and provision of a 'buddy' to carry literature to court and act as a scribe for verbal information. John also began making positive changes himself, such as reviewing his routine and identifying opportunities to work from home or use a quiet office at work.

John reflects:

"I feel like a weight has been lifted from my shoulders. The advice provided enabled me to discuss my difficulties with my employer and present possible solutions. I realise I need to plan for the future and my wife is now re-training, so that working part-time will be an option for me, if my situation changes."

QUALITY REQUIREMENT 7:

Providing equipment and accommodation

People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.

THE ROLE OF THE THERAPIST [7,17,66,67]

- Advice on independent living equipment to improve independence and safety
- Expertise in positioning and seating to enable mobility and prevent complications
- Case management which maximises independence and quality of life
- Risk assessment and manual handling training
- Co-ordination of an integrated approach across health and social care
- Education of staff in social services on the unique long-term needs of people with MS living in the community
- Holistic home assessments for:
  - appropriate assistive technology, communication aids and environmental control equipment
  - safety and risk
  - Disabled Facilities Grants to fund major home adaptations

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with a specialist knowledge of MS
- Timely provision and review of assistive technology and equipment in accordance with nationally agreed standards and guidelines
- Holistic therapy services enabling an individual to live their life to the full in terms of work, leisure and personal care
- Therapist case managers
- Integrated equipment services
- Rapid access to social service assessments – through integrated health and social care working
- Wheelchair services that can accommodate the variable needs of people with MS
- Specialist education of the person with MS and their family to achieve their goals
- Specialist education of carers to ensure they can provide effective care and support for the person with MS

CASE STUDY:

Delays in providing necessary adaptations lead to a crisis situation

Paul recently endured a gradual decline in his functional ability due to upper and lower limb weakness, poor trunk control and leg spasms. He attended the local physiotherapy department at a nearby cottage hospital for treatment.

An assessment established that Paul was at risk of falling when walking and bathing. It also highlighted that he was unable to maintain his balance when seated, due to leg spasms that increased his risk of falling out of his chair. The physiotherapist identified a decrease in functional ability and referred Paul for a home adaptations/aids assessment by an occupational therapist from social services.

"Previously, Paul had refused the offer of independent living equipment as he felt this would be like giving up and that they signified the slippery slope to dependency."

The occupational therapist introduced some simple equipment and adaptations straight away, but major modifications were required to improve access into and within Paul's home. An application for a Disabled Facilities Grant (DFG) was made, to pay for these major adaptations. Unfortunately the waiting time for the grant was 12 months, despite the fact that Paul would remain at risk of falls during this time.

The therapists involved did everything they could to minimise this continued risk. However, despite these measures, four weeks later Paul fell at home and injured himself, resulting in emergency admission to hospital.

What difference could an MS specialist therapist have made?

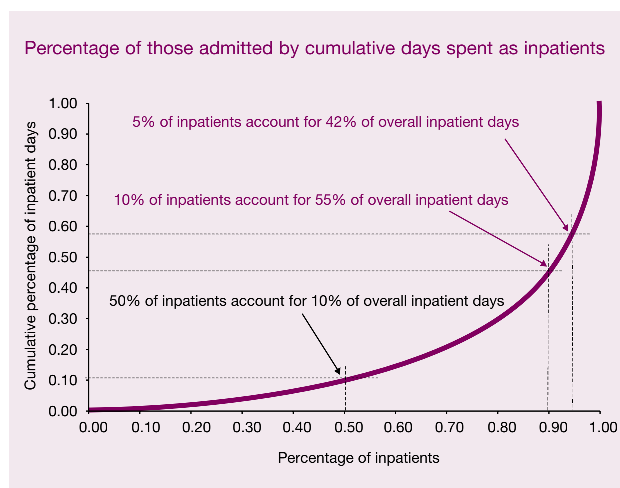
- Regular contact with Paul to monitor his condition would have identified his decline in functional ability at an earlier stage
- Pro-active discussions with Paul about his earlier reluctance to accept any adaptations and equipment could have persuaded him to accept help before a crisis point was reached
- Effective co-ordination of treatment options for Paul, either at home or as a planned inpatient admission for rehabilitation treatment
- An MS specialist therapist could have acted as a resource for other professionals involved in Paul's care, to assist in trouble-shooting the problems involved
- Facilitation of a supporting letter from Paul's neurologist, to stress the urgency of the crisis situation, may have been appropriate.
- If required, support could have been given when making the DFG application, to ensure that it included adaptations needed for times of increased difficulty. This is much more cost-effective and avoids the need for further crisis management in the future.

QUALITY REQUIREMENT 8:
Providing personal care and support

Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

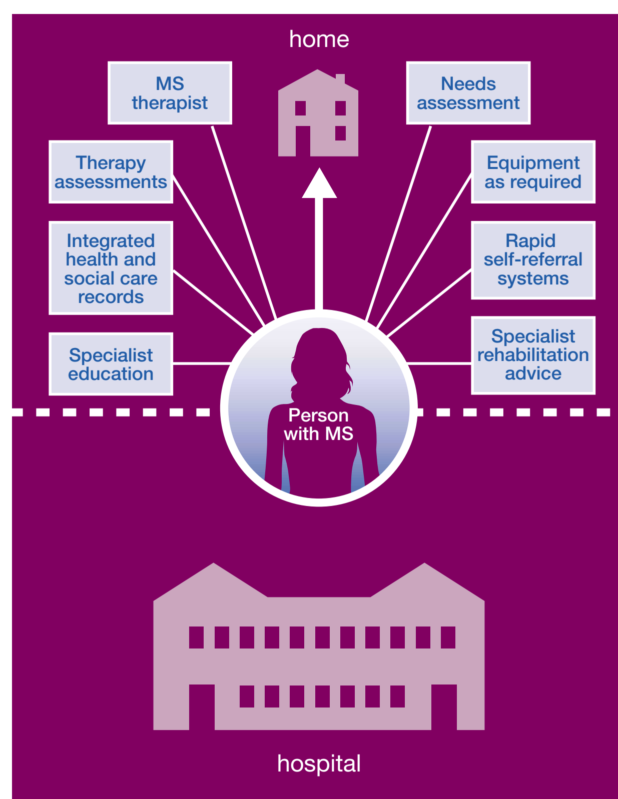
THE ROLE OF THE THERAPIST[18,19,43,68,69]

- Case management to ensure inter-disciplinary working which incorporates social care professionals and the voluntary sector
- Problem-solving to produce innovative models of care provision
- Anticipation of problems and a proactive approach
- Holistic assessment of cognitive and physical limitations
- Support to help the person with MS to communicate their choices
- Education and support of carers
- Support to enable a person with MS to remain in their home of choice



RECOMMENDATIONS FOR THERAPY SERVICE:

- Access to therapists with a specialist knowledge of MS
- Availability of therapy assessments within an individual's home environment
- Effective liaison with social care services co-ordinated by the case manager, including integrated health and social care records
- Specialist education of the person with MS and their family to achieve their goals
- Consideration of long and short-term requirements when undertaking the assessment of needs
- Rapid self-referral by people with MS or via the GP
- Availability of equipment as required
- Availability of specialist rehabilitation advice within the community



CASE STUDY:

Providing personal care to enable a person with MS to continue living at home

Anna had successfully managed her MS symptoms at home for a number of years. However, her situation changed when she fell and sustained multiple fractures to her right leg. This fall led to a hospital admission where concerns were raised over the deterioration, both to her MS symptoms and also her psychological health.

She was assessed by the hospital therapy team and social worker with regard to self-care, mobility and potential future risks once back at home. A case conference was arranged while Anna was in hospital, chaired by her case manager, an MS specialist occupational therapist employed by the local authority. As a result, it was recommended that Anna would need a care package consisting of three calls a day to assist her with her personal care needs and preparing meals and drinks.

It was agreed that due to the complex nature of Anna's MS and the multiple fractures she had sustained, the home care staff would need further assistance and training in manual handling techniques. Anna's case manager arranged several training sessions for her carers working in conjunction with the hospital staff prior to her discharge, and assumed responsibility for reviewing and monitoring this once Anna was at home.

Once back in her own home, Anna's progress was monitored by her case manager, who identified that cognitive impairment was causing Anna to become frustrated and angry. During home visits the case manager allowed Anna to express her fears and anxieties and offered advice, support and coping strategies to help minimise some of these difficulties. Anna also accepted an invitation to attend a resource day care centre for people with physical disabilities to increase her social opportunities.

The case manager encouraged the home care staff to start involving Anna in basic daily living tasks and decisions about her daily needs, to give her an element of control and increase her confidence. They were also invited to attend a local carer's support group to learn more about MS and share their own experiences.

Anna's case manager:

"Anna has regained an element of independence in some activities of daily living, increasing both her sense of control and quality of life. Continued regular inter-disciplinary review meetings and the time spent in one-to-one home visits has really opened up communication about Anna's anxieties and aspirations, enabling us to support her in the most effective way possible."

Anna's home carer:

"I feel like I have some support now. When I do ask for help and advice, the case manager ensures I get it."

QUALITY REQUIREMENT 9:
Palliative care

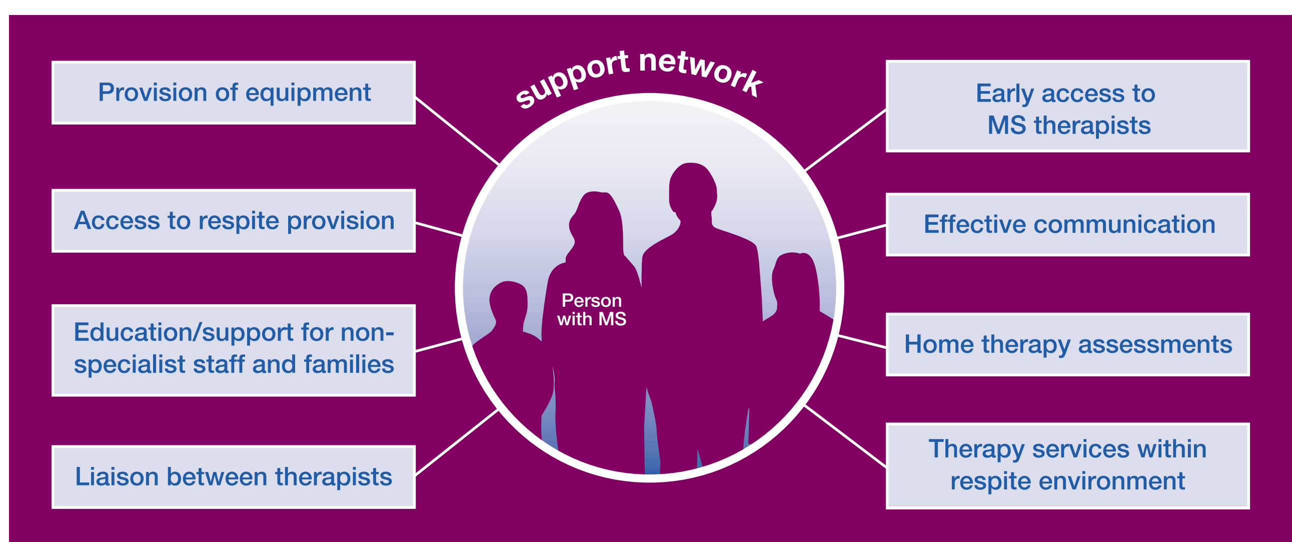
People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

THE ROLE OF THE THERAPIST[39,41,70-74]

- Holistic assessment incorporating the needs of family/carers
- Maintenance of effective methods of communication
- Contribution to the management of nutrition, balancing safety and quality of life requirements
- Maintenance of significant life roles wherever possible
- Assessment for equipment to maintain quality of life
- Optimisation of control over the surrounding environment for the person with MS
- Prevention of secondary complications
- Facilitation of effective pain management
- Maintenance of respiratory function
- Acting as a resource for end of life social/ spiritual issues

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with specialist knowledge of MS. In particular, speech therapy services to be available early enough to prevent crises
- Effective systems to ensure effective communication between therapy services and the palliative care team
- Therapy assessments undertaken in the home environment
- Timely provision and funding of equipment
- Access to respite provision
- Therapy services available within the respite environment
- Specialist therapists to educate ward staff should admission to hospital be necessary
- Specialist therapists to educate non specialist staff, families and carers
- Close liaison between therapists to ensure maintenance of quality of life



CASE STUDY:

A man with rapidly progressive MS benefits from palliative care

Stuart has a five-year history of MS that has progressed rapidly in the last 12 months. Wheelchair-dependent for all mobility, he requires a hoist for transfers and assistance for all activities of daily living at home (which has been fully adapted). Since diagnosis, Stuart has been in regular contact with therapists at the local outpatient department, who had addressed his needs, including respiratory physiotherapy for several chest infections.

Due to Stuart's recent decline, a referral was made to a specialist community MS team. To date, the pivotal contribution from this team has been from the speech and language therapist (SLT), who has addressed his swallowing difficulties and deteriorating speech.

Stuart reported frequent choking when eating or drinking, which made meal times embarrassing. He often gave up before finishing meals and had started to lose weight as a result. This also upset him as he had previously enjoyed meals with friends and family. The SLT carried out a swallowing evaluation followed by a specialist X-Ray, to reveal the nature of Stuart's swallowing difficulties. The need to minimise choking episodes was balanced with the desire to continue with family meals. In discussion with Stuart and his family, it was agreed that a *gastrostomy** would be inserted to maintain hydration and supplement nutrition. The SLT worked with a dietitian to provide advice on safe food textures to enable a continued level of oral nutrition.

Stuart was also experiencing speech problems which at times made participation in conversation difficult. Contributing to discussions was crucial as it helped maintain his self-esteem, sustain relationships and retain control over his environment. Speech and language therapy helped maximise Stuart's communication with strategies to improve speech production and interaction. Stuart's family were educated on facilitating his participation in conversation. An electronic communication aid was also provided, to be used at times when his speech became unintelligible.

The SLT has liaised closely with the rest of the community MS team regarding Stuart's case. As a result, the MS specialist physiotherapist has done some additional work to reassure Stuart's wife that she is competent to undertake a daily stretch programme to prevent contractures. Close contact with Stuart will continue to ensure that his quality of life is the best that it can be.

*A percutaneous endoscopic gastrostomy (PEG) involves a minor operation where a small feeding tube is inserted directly into the stomach through the abdominal wall.

QUALITY REQUIREMENT 10: Supporting families and carers

Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carers and in their own right.

THE ROLE OF THE THERAPIST[19,75-77]

- Case management which takes family relationships into consideration
- Assessment of carers' needs
- Facilitation of communication amongst families and with professionals
- Provision of support groups for carers
- Education and advice on topics such as:
  - manual handling techniques
  - cognitive impairment and coping strategies
  - respiratory management
  - posture and positioning
- Signposting to the relevant services and resources

RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with specialist knowledge of MS
- Specialist education of carers to ensure that they can provide effective care and support for the person with MS
- Specialist therapy assessments of individuals to ensure that the carer can provide the necessary support
- Effective liaison between health and social care services, managed by the case manager
- Appropriate respite services with an understanding of the person's circumstances
- Ongoing access to advice, for example information for carers on finances and respite support
- Education of therapists to facilitate discussion with carers about the impact of MS and how to manage "loss"

CASE STUDY:

The husband of a woman with MS is provided with support and reassurance in his role as carer

"When Georgina was first diagnosed with MS we thought our world had fallen apart, but as the years went by, it seemed she had a mild form of the condition.

When I retired, I started to help out more around the house, and I noticed how much more difficult everything was becoming for her. She seemed to need me for every little activity she was doing, and she wasn't as keen to get out and about in the evenings as much as I had hoped. We had always dreamed of an around-the-world cruise when I retired, but she suddenly became very resistant to booking anything, and I found myself getting irritated because she seemed to be holding me back.

About a month ago Georgina suddenly had a very disabling relapse and lost all use of her legs, so went into hospital. That was quite a shock, as we'd never really had anything much to do with the health service. She had some treatment, but her legs didn't recover as strongly as before, and she had to rely on a wheelchair in the afternoons on the ward. She didn't seem to be aware of what this all meant for us, and I was really starting to panic about what we were going to do when the time came to leave.

My son spoke to the ward manager and she arranged for the MS specialist occupational therapist and physiotherapist to assess Georgina when I was visiting. They had already been working with Georgina and were marvellous – they knew exactly what I was feeling, and gave us lots of support and practical advice, like how to get in and out of the car so we could still go out. They brought Georgina home for a visit, so we could try out some of the techniques they had showed us in the hospital, and arrange for some equipment to be provided.

I'll admit that it took me some time to cope with the realisation that Georgina was now "disabled" and what that meant for our life. I was very anxious about being responsible for looking after her, and not being able to play golf or get to my cricket matches. The therapists said that a social worker could do a carer's assessment to see what my needs were and the support I could get to manage Georgina at home. They also mentioned that respite care was available if I needed it and gave me the details of a local MS service in case we needed more advice in the future."

"It took me some time to cope with the realisation that Georgina was now "disabled" and what that meant for our life. I was very anxious about being responsible for looking after her."

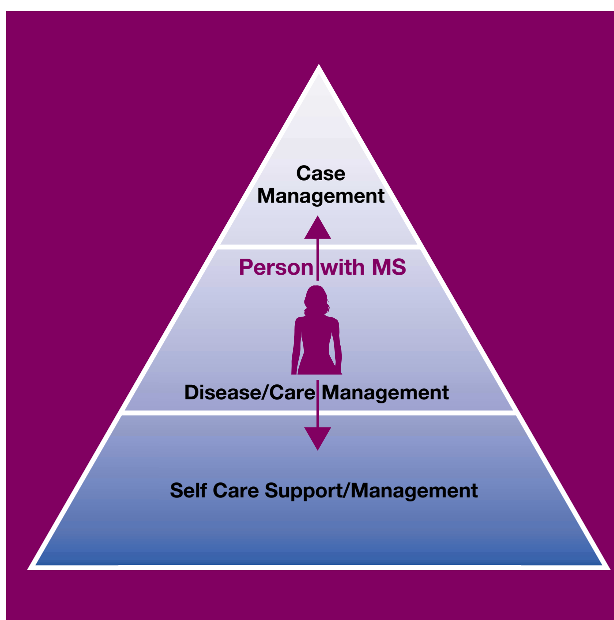
QUALITY REQUIREMENT 11:

Caring for people with neurological conditions in hospital or other health and social care settings

People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

THE ROLE OF THE THERAPIST[13,44-47]

- Promotion of a wider health awareness for people affected by MS
- Case management to ensure professionals in non 'neurological settings' are aware of the implications of MS
- Provision of advice and education to professionals with no experience in MS
- Support to ensure that the person with MS can make informed choices about their care
- Problem-solving approach if MS symptoms create a barrier to treatment or care required
- Seeking advice and information about a co-existing diagnosis to understand its potential impact on MS



RECOMMENDATIONS FOR THERAPY SERVICE

- Access to therapists with specialist knowledge of MS
- Effective communication between specialist therapy services and professionals in other health and social care settings to ensure that the individual with MS is provided with appropriate care for all conditions
- Effective training and advice for non specialist staff by specialist therapists
- Case management to ensure good communication between all agencies

CASE STUDY:

A hospital ward manager describes her experience of arranging care for a patient with MS

"I am the manager of a gynaecological ward in a small local hospital. When Monica was admitted for a routine hysterectomy, we realised that she was struggling to cope with her MS at home, although she had the support of community carers.

She presented with severe spasticity, mainly affecting her legs. Although she had a good quality wheelchair with a lot of adaptations, she didn't seem to be very comfortable sitting in it for any length of time, and suffered from painful spasms quite regularly. As part of her routine pre-op assessment, our ward physiotherapist stated that in her opinion, Monica's spasticity needed to be addressed.

She asked the physiotherapist and occupational therapist from the neurology ward to advise us about Monica's MS. After assessing her, they recommended that Monica should be seen in a specialist spasticity clinic, and arranged an outpatient appointment at a centre of excellence for after her hysterectomy. They felt that, in view of her level of disability, she would benefit from an assessment for environmental controls, although there were concerns about her cognitive ability and her capacity to learn to use such a system. They also provided some tips on ways of managing Monica's spasticity on the ward and wrote a report for Monica's spasticity appointment.

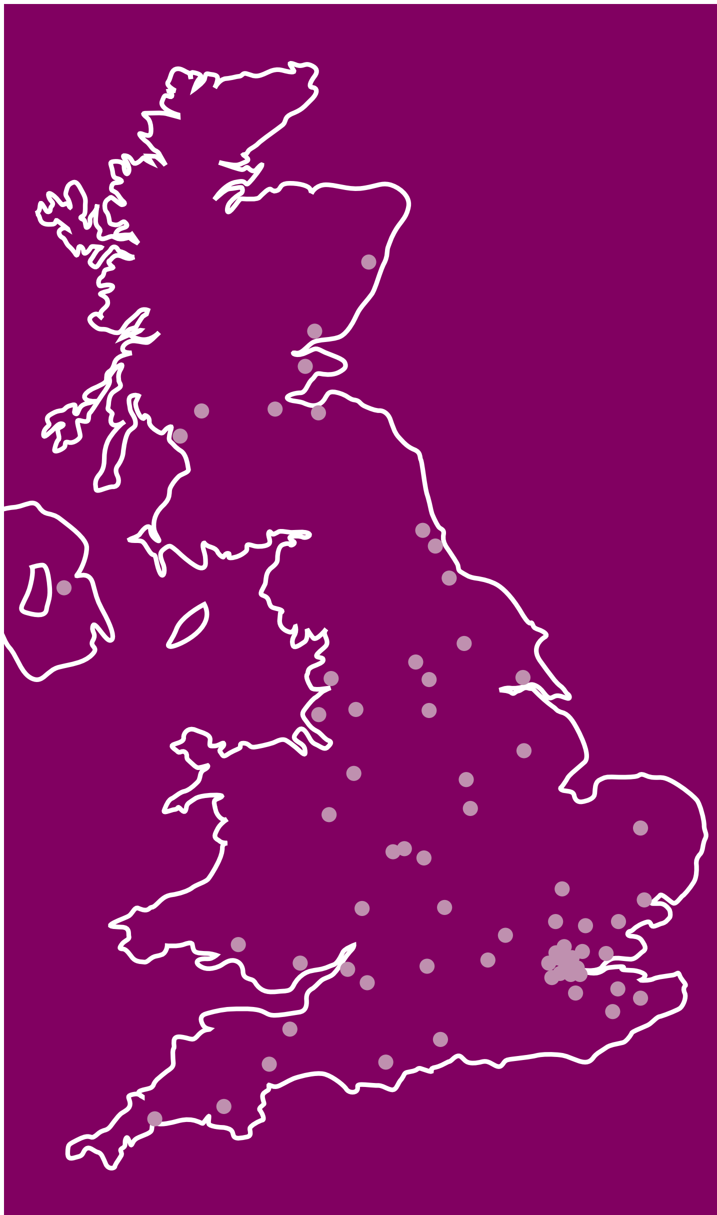
The specialist spasticity team discussed management options with Monica, including intrathecal baclofen and intrathecal phenol. They agreed that her wheelchair, posture and seating should be reviewed in conjunction with any medical intervention, and that this could be carried out as part of a planned inpatient admission to their hospital. They also offered an environmental control assessment (in the context of her cognitive impairment) and agreed to liaise with local providers regarding her potential to use the system."

"Monica was very positive about the outcome of the spasticity assessment and felt that new doors were being opened to her. I was pleased that we had been able to link her in to the right services for her specific needs."

Appendices

Appendix 1

In February 2002 the Department of Health, in association with the health departments of Scotland, Northern Ireland and Wales launched a Risk-sharing Scheme to ensure that all eligible people with MS, as assessed by the Association of British Neurologists guidelines, should have access to disease modifying drug therapy on the NHS (Avonex, Betaferon, Copaxone and Rebif). The specialised MS centres participating in the Department of Health Risk-sharing Scheme are shown below.



- Aberdeen - Aberdeen Royal Infirmary
- Basildon - Basildon Hospital
- Bath - Royal United Hospital
- Belfast - Royal Victoria Hospital
- Birmingham - Queen Elizabeth Hospital
- Bristol - Frenchay Hospital
- Bromley - Bromley Hospital
- Cambridge - Addenbrookes Hospital
- Canterbury - Kent & Canterbury Hospital
- Cardiff - University Hospital of Wales
- Chelmsford - Broomfield General Hospital
- Colchester - Colchester General Hospital
- Coventry - Walsgrave Hospital
- Dundee - Ninewells Hospital
- Dunfermline - Queen Margaret Hospital
- Edinburgh - Western General Hospital
- Exeter - Mardon House
- Falkirk - Falkirk & District Royal Infirmary
- Frimley - Frimley Park Hospital
- Gillingham - Medway Maritime Hospital
- Glasgow - Southern General Hospital
- Gloucester - Gloucestershire Royal Hospital
- Harlow - Princess Alexandra Hospital
- High Wycombe - Amersham Hospital
- Hull - Hull Royal Infirmary
- Ilford - King Georges Hospital
- Ipswich - Ipswich Hospital
- Irvine - Ayrshire Central Hospital
- Leeds - St James' University Hospital
- Leicester - Leicester Royal Infirmary
- Lewisham - University Hospital
- Lincoln – Lincoln County Hospital
- Liverpool - The Walton Centre
- London - Atkinson Morley Hospital
- London - Central Middlesex Hospital
- London - Charing Cross Hospital
- London - Chelsea & Westminster Hospital
- London - Guy's Hospital
- London - Kings College Hospital
- London - National Hospital for Neurology & Neurosurgery
- London - Royal Free Hospital
- London - Royal London Hospital
- London - St Thomas' Hospital
- Manchester - Hope Hospital
- Middlesbrough - James Cook University Hospital
- Newcastle upon Tyne - Royal Victoria Infirmary
- Norwich - Norfolk & Norwich Hospital
- Nottingham - Queens Medical Centre
- Oxford - Radcliffe Infirmary
- Plymouth - Derriford Hospital
- Poole - Poole Hospital
- Preston - Royal Preston Hospital
- Reading - Battle Hospital
- Romford - Oldchurch Hospital
- Sheffield - Royal Hallamshire Hospital
- Southampton - Southampton General Hospital
- Southend - Southend Hospital
- Stoke on Trent - North Staffordshire Royal Infirmary
- Sunderland - Sunderland Royal Infirmary
- Swansea - Morriston Hospital
- Swindon - Great Western Hospital
- Taunton - Taunton & Somerset Hospital
- Telford - Princess Royal Hospital
- Truro - Royal Cornwall Hospital
- Tunbridge Wells - Kent & Sussex Hospital
- Wakefield - Pinderfields General Hospital
- Woolwich - Queen Elizabeth Hospital
- York - York District Hospital

Appendices

Appendix 2

Allied Health Professions

The Health Professions Council currently regulates the following allied health professions:
Arts therapists
Chiropodists/podiatrists
Dietitians
Occupational therapists
Orthoptists
Paramedics
Physiotherapists
Prosthetists and orthotists
Radiographers
Speech and language therapists

Available at: http://www.hpc-uk.org/aboutregistration/professions/

Appendix 3

Commissioning MS Services

1. If you are commissioning MS services and would like to contact a specialist therapist for assistance, this can be done via a number of routes. In most strategic health authorities, there is a lead Allied Health Professional who will identify an appropriate individual through their local forum. There are also currently clinical managers in each PCT who can be contacted direct.

2. If you would like to contact a specialist therapist outside of your immediate area, the Therapists in MS group have developed a Contact Directory of therapists across the UK who have expertise in MS. Please contact the MS Trust on 01462 476700, who will access this directory on your behalf to locate an appropriate therapist.

3. The Therapists in MS Contact Directory can also be used to locate therapists with experience in delivering particular types of MS services. If you are planning to establish or change an MS service in your area, you can contact the MS Trust on 01462 476700, who can put you in touch with a specialist therapist with expertise in the following areas:

   a) The different types of MS service include:

   - An inter-disciplinary MS team*
   - Cross agency services*
   - Specialist rehabilitation*
   - Self-referral systems

   *Both primary and secondary care based

   b) Specialist therapy approaches for MS include:

   - Botulinum toxin injection services
   - Carer support groups
   - Cognition management
   - Communication groups
   - Employment/occupation services
   - Equipment and adaptation services
   - Exercise and fitness services
   - Fatigue management
   - Functional electrical stimulation
   - Gait services (specialist)
   - Orthotics
   - Pain management
   - Palliative services
   - Relapse management
   - Seating and posture
   - Spasticity services
   - Swallowing services

Service examples from the NSF for Long-term Conditions

Therapists are integral to the following service examples taken from a Good Practice Guide that the Department of Health is developing to accompany the NSF for Long-term Conditions. Additional service examples and further details are available on the Department of Health website at:

www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice

Quality Requirement 1 – Person-centred

- Service Example: Neurology Outreach Service, Sheffield
- Service Example: Camden Physical Disability and Brain Injury Team, London

Quality Requirement 2 - Early recognition and diagnosis

- Service Example: Community MS Team (CMST), Regional Neurological Rehabilitation Centre, Newcastle
- Service Example: The Spasticity Service, The National Hospital for Neurology and Neurosurgery, London

Quality Requirement 4 - Early and specialist rehabilitation

- Service Example: Regional Rehabilitation Unit, Northwick Park Hospital, Harrow, London

Quality Requirement 5 – Community rehabilitation

- Service Example: Independent Living Team, Nottingham
- Service Example: Disabled Adults Resource Team, Bristol
- Service Example: Multiple Sclerosis Young Woman/Mother and Toddler Group, Stockport

References

References

1. Department of Health. National Service Framework for long-term conditions. London: Department of Health; 2005.
2. NHS Scotland. Delivering for Health. Edinburgh: Department of Health, Scottish Executive; 2005.
3. NHS Wales. Designed for life: creating world-class health and social care for Wales in the 21st century. Cardiff: Welsh Assembly Government; 2005.
4. Department of Health, Social Services and Public Safety. Caring for people beyond tomorrow: a strategic framework for the development of primary health and social care for individuals, families and communities in Northern Ireland. Belfast: Department of Health, Social Services and Public Safety; 2005.
5. National Institute for Clinical Excellence. Multiple sclerosis: management of multiple sclerosis in primary and secondary care. London: NICE; 2003.
6. Burgess M. Multiple sclerosis: theory and practice for nurses. London: Whurr publishers; 2002.
7. Silcox L. Occupational therapy and multiple sclerosis. London: Whurr publishers; 2003.
8. NHS Modernisation Agency. The clinicians guide to applying the 10 high impact changes. London: NHS Modernisation Agency; 2005.
9. Craig J, Young CM, Ennis M, Baker G, Boggild M. A randomised controlled trial comparing rehabilitation against standard therapy in multiple sclerosis patients receiving intravenous steroid treatment. J Neurol Neurosurg Psychiatry 2003; 74(9):1225-30.
10. Slade A, Tennant A, Chamberlain MA. A randomised controlled trial to determine the effect of intensity of therapy upon length of stay in a neurological rehabilitation setting. J Rehabil Med 2002; 34(6): 260-6.
11. Craig J. Development of a relapse clinic for people with multiple sclerosis. BrJ Ther Rehabil 2002; 9(9): 333.
12. Department of Health. The NHS knowledge and skills framework (NHS KSF) and the development review process. London: Department of Health; 2004.
13. Skills for Health [Online]. Competences framework: LTCN Long term conditions - neurological care. [Cited 10 January 2006]; available from: www.skillsforhealth.org.uk.
14. Allied Health Professions Federation. Working differently: the role of allied health professionals in the treatment and management of long-term conditions. London: Allied Health Professions Federation; 2005.
15. LaBan MM, Martin T, Pechur J, Samacki S. Physical and occupational therapy in the treatment of patients with multiple sclerosis. Phys Med Rehabil Clin N Am 1998; 9(3): 603-14.
16. La Rocca N, Kalb RC, Gregg K. A program to facilitate retention of employment among persons with multiple sclerosis. Work 1996; 7(1): 37-46.
17. Evans RL, Connis RT, Hendricks RD, Haselkorn JK. Multidisciplinary rehabilitation versus medical care: a meta-analysis. Soc Sci Med1995; 40(12): 1699-706.
18. Klugman TM, Ross E. Perceptions of the impact of speech, language, swallowing and hearing difficulties on quality of life of South African persons with multiple sclerosis. Folia Phoniatr Logop 2002; 54(4): 201-21.
19. Our health, our care, our say: a new direction for community services. Cm 6737. 2006.
20. NHS Modernisation Agency and Skills For Health. Case management competencies framework for the care of people with long-term conditions. Bristol: NHS Modernisation Agency and Skills For Health; 2005.
21. Department of Health. Supporting people with long-term conditions: an NHS and social care model to support local innovation and integration. London: Department of Health; 2005.
22. Department of Health. A policy framework for commissioning cancer services: a report by the Expert Advisory Group on cancer to the Chief Medical Officers of England and Wales. [The Calman-Hine report]. London: Department of Health;1999.
23. Health Service Circular 2002/004. Cost effective provision of disease modifying therapies for people with multiple sclerosis. London: Department of Health.
24. Richards RG, Sampson FC, Beard SM, Tappenden P. A review of the natural history and epidemiology of multiple sclerosis: implications for resource allocation and health economic models. Health Technology Assess 2002; 6(10): 1-73.
25. McDonnell GV, Hawkins SA. An epidemiologic study of multiple sclerosis in Northern Ireland. Neurology 1998; 50; 423-8.
26. Robertson N, Compston A. Surveying multiple sclerosis in the United Kingdom. J Neurol Neurosurg Psychiatry 1995; 58: 2-6.
27. Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: results of an international survey. Neurology 1996; 46: 907-11.
28. Hemmett L, Holmes J, Barnes M, Russell N. What drives quality of life in multiple sclerosis? QJM 2004; 97: 671-6.
29. MS Trust. Multiple sclerosis information for health and social care professionals. Letchworth: Multiple Sclerosis Trust; 2004.
30. Goodin DS, Frohman EM, Garmany GP Jr, Halper J, Likosky WH, Lublin FD et al. Disease modifying therapies in multiple sclerosis: report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology and the MS Council for Clinical Practice Guidelines. Neurology 2002; 58(2): 169-78.
31. Thompson AJ. Rehabilitation of progressive neurological disorders: a worthwhile challenge. Curr Opin Neurol 1996; 9(6): 437-40.
32. Makepeace RW, Barnes MP, Semlyen JK, Stevenson J. The establishment of a community multiple sclerosis team. Int J Rehabil Res 2001; 24(2): 137-41.
33. College of Occupational Therapists. Definition and core skills for occupational therapy. London: College of Occupational Therapists; 2004.
34. Physiotherapy Explained. Chartered Society of Physiotherapy website. [Cited 16 November 2005]. Available from: www.csp.org.uk.
35. Yorkston K et al. Management of speech and swallowing disorders in degenerative disease. 2nd ed. Austin TX: Pro-Ed; 2003.
36. Wade DT. Cognitive assessment and neurological rehabilitation. Clin Rehabil 2002; 16(2): 117-8.
37. Mathiowetz VG, Finlayson ML, Matuska KM, Chen HY, Luo P. A randomized controlled trial of an energy conservation course for persons with multiple sclerosis. Mult Scler 2005; 11(5): 592-601.
38. Al-Smadi J, Warke K, Wilson I, Cramp AF, Noble G, Walsh DM et al. A pilot investigation of the hypoalgesic effects of transcutaneous electrical nerve stimulation upon low back pain in people with multiple sclerosis. Clin Rehabil 2003; 17: 742-9.
39. Thompson AJ, Jarrett L, Lockley L, Marsden J, Stevenson VL. Clinical management of spasticity. J Neurol Neurosurg Psychiatry 2005; 76(4): 459-63.
40. Murdoch B et al (ed) Speech and language disorders in multiple sclerosis. London: Whurr publishers; 2000.
41. Calcagno P, Ruoppolo G, Grasso MG, De Vincentiis M, Paolucci S. Dysphagia in multiple sclerosis - prevalence and prognostic factors. Acta Neurol Scand 2002; 105(1): 40-3.
42. O'Hara L, Cadbury H, De Souza L, Ide L. Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial. Clin Rehabil 2002; 16: 119-28.

References

43. Turner-Stokes L, Williams H, Abraham R. Clinical standards for specialist community rehabilitation services in the UK. Clin Rehabil 2001; 15(6): 611-23.

44. College of Occupational Therapists. COT/BAOT Briefings: Occupational therapy clinical specialists. London: College of Occupational Therapists. 2003. (Currently under review)

45. Chartered Society of Physiotherapists. Specialisms and specialists. 2nd ed. London: Chartered Society of Physiotherapists; 2001.

46. Royal College of Speech and Language Therapists. Communicating Quality 2. London: Royal College of Speech and Language Therapists; 1996. (Currently under review, Communicating Quality 3 due out in 2006).

47. Miller C. Specialists and Generalists. Br J Rehabil Ther 1995; 2(3): 145-8.

48. D'Arcy C. Managing multiple sclerosis: working in partnership. Nurs Manag 2005; 12(6): 32-5.

49. Freeman JA. Improving mobility and functional independence in persons with multiple sclerosis. J Neurol 2001; 248(4):255-9.

50. Petajan JH, Gappmaier E, White AT, Spencer MK, Mino L, Hicks RW. Impact of aerobic training on fitness and quality of life in multiple sclerosis. Ann Neurol 1996; 39: 432-41.

51. Vanage SM, Gilbertson KK, Mathiowetz V. Effects of an energy conservation course on fatigue impact for persons with progressive multiple sclerosis. Am J Occup Ther 2003; 57(3): 315-23.

52. Wiles CM, Newcombe RG, Fuller KJ, Shaw S, Furnival-Doran J, Pickersgill TP et al. Controlled randomised crossover trial of the effects of physiotherapy on mobility in chronic multiple sclerosis. J Neurol Neurosurg Psychiatry 2001; 70(2): 174-9.

53. Johnson KL, Yorkston KM, Klasner ER, Kuehn CM, Johnson E, Amtmann D. The costs and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis. Arch Phys Med Rehabil 2004; 85(2): 201-9.

54. Brown T, Kraft GH. Exercise and rehabilitation for individuals with multiples sclerosis. Physical Medicine and Rehabilitation Clinics of North America 2005; 16: 513-55.

55. Kesselring J, Beer S. Symptomatic therapy and neuro-rehabilitation in multiple sclerosis. Lancet Neurol 2005; 4(10): 643-52.

56. Thompson AJ. Neurorehabilitation in multiple sclerosis: foundations, fact and fiction. Curr Opin Neurol 2005; 18(3): 267-71.

57. Turner-Stokes L, Williams H, Abraham R, Duckett S. Clinical standards for inpatient specialist rehabilitation services in the UK. Clin Rehabil 2000; 14(5): 468-80.

58. Edwards SG, Thompson AJ, Playford ED. Integrated care pathways: disease-specific or process-specific? Clin Med 2004; 4(2): 132-5.

59. Rossiter DA, Edmondson A, al-Shahi R, Thompson AJ. Integrated care pathways in multiple sclerosis rehabilitation: completing the audit cycle. Mult Scler 1998; 4(2): 85-9.

60. Freeman JA, Langdon DW, Hobart JC, Thompson AJ. Inpatient rehabilitation in multiple sclerosis: do the benefits carry over into the community? Neurology 1999; 52(1): 50-6.

61. Einarsson U, Gottberg K, Fredrikson S, Bergendal G, von Koch L, Holmqvist LW. Multiple sclerosis in Stockholm County. A pilot study exploring the feasibility of assessment of impairment, disability and handicap by home visits. Clin Rehabil 2003; 17(3): 294-303.

62. Finlayson M. Concerns about the future among older adults with multiple sclerosis. Am J Occup Ther 2004; 58(1): 54-63.

63. Johnson KL, Fraser RT. Mitigating the impact of multiple sclerosis on employment. Phys Med Rehabil Clin N Am 2005; 16: 571-82.

64. Roessler RT, Rumrill PD Jr. Multiple sclerosis and employment barriers: a systematic perspective on diagnosis and intervention. Work 2003; 21(1): 17-23.

65. Jongbloed L. Factors influencing employment status of women with multiple sclerosis. Can J Rehabil 1996; 9(4): 213-22.

66. Blake DJ, Bodine C. An overview of assistive technology for persons with multiple sclerosis. J Rehabil Res Dev 2002; 39(2): 299-312.

67. Finlayson M, Gugielmello L, Liefer K. Describing and predicting the possession of assistive devices among persons with multiple sclerosis. Am J OccupTher 2001; 55(5): 545-51.

68. Law M. Participation in the occupations of everyday life. Am J Occup Ther 2002; 56(6): 640-9.

69. Yorkston KM, Klasner ER, Swanson KM. Communication in context: a qualitative study of the experiences in individuals with multiple sclerosis. Am J Speech-Lang Path 2001; 10(2): 126-37.

70. Prosiegel M, Schelling A, Wagner-Sonntag E. Dysphagia and multiple sclerosis. Int MS J 2004; 11(1): 22-31.

71. Payne A. Nutrition and diet in the clinical management of multiple sclerosis. J Hum Nutr Diet 2001; 14(5): 349-57.

72. Collin C. PEG feeding in multiple sclerosis – too little, too late? Way Ahead 2005; 9(1): 4-5.

73. Multiple sclerosis “we all live in hope”. Chapter 4 in: Small N et al, editors. Too ill to talk? User involvement and palliative care. London: Routledge; 2000.

74. Rousseaux M, Perennou D. Comfort care in severely disabled persons with multiple sclerosis. J Neurol Sci 2004; 222(1-2): 39-48.

75. McKeown L, Porter-Armstrong AG, Baxter GD. Caregivers of people with multiple sclerosis: experiences of support. Mult Scler 2004; 10(2): 219-230.

76. McKeown L, Porter-Armstrong AG, Baxter GD. The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. Clin Rehabil 2003; 17(3): 234-48.

77. Reid D, Laliberte-Rudman D, Hebert D. Impact of wheeled seated mobility devices on adult users' and their caregivers' occupational performance: a critical review. CanJ OccupTher 2002; 69(5): 261-80.

Published in the United Kingdom by

Multiple Sclerosis Trust
Spirella Building
Bridge Road
Letchworth
SG6 4ET
Tel: 01462 476700
Email: info@mstrust.org.uk
Website: www.mstrust.org.uk

Registered Charity Number 1088353

© 2006 Multiple Sclerosis Trust

All rights reserved. No part of this book may be produced, stored in a retrieval system or transmitted in any form by any means, electronic, magnetic tape, mechanical, photocopying, recording or otherwise without written permission of the publisher.

Design and Production – Michael Cotts

Multiple Sclerosis Trust
opening the door to information education and research

tims
Therapists in ms