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to delivery of a person centred relapse service

B Porter, F Matheson, J Chataway and others

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Forewords

Too often 'person-centred' is little more than rhetoric. From the point of view of a person with MS going into a relapse, what would person-centred *really* mean?

"Can I have a fast referral to a specialist to confirm or refute a relapse?"
"Can I have a proper assessment and discuss whether steroids are right for me now?"
"If so, can I have steroids immediately?"
"If it's IV steroids and I'm well enough, can I have them at home?"

Every person with MS is different, with different needs at different times, living in families or alone, in cities or remote places. But all - as far as possible - need choice about treatment, care delivered close to where they live and specialist support in self-management.

The key steps outlined here have the potential to meet these needs: care delivered by a specialist multi-disciplinary team in a cost effective manner, meeting the key priorities of the NICE MS Clinical Guidelines and the quality requirements of the National Service Framework.

The MS Trust is delighted to have been involved in the development of this blueprint for a person - centred relapse service, both through the research that underpins some of the work and, now, in promoting its findings.

Chris Jones
Trustee, MS Trust

Pam Macfarlane
Chief Executive, MS Trust

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The National Service Framework for people with long-term neurological conditions is ambitious because it addresses conditions ranging from the sudden onset of a brain injury, through to progressive conditions such as MS. Within this, there is the challenge of the unpredictable pattern of MS with sudden relapses devastating the lives of individuals and families. Too often there are long delays as notes are found, appointments made and diagnoses reached, before treatment and support is provided. The idea of the NSF's care plan, which will travel with the individual as they move along the care pathway, is especially critical for someone facing a relapse. The careplan should ensure a flexible, rapid response to a change in symptoms, providing the care and support needed to continue to live as independently as possible.

Delivering this sort of response requires new ways of doing things. This blue-print for a relapse service is a prime example of how an holistic approach to care can transform lives. The shift to outpatient and home care, reduction in waiting times from six weeks to six days, self-referral and use of tele-triage, not only meets the requirement of the individual but is cost-effective.

I commend to you this 'Key Steps' document and hope it will help you in developing your own new ways to better support people with MS.

Diana Whitworth
Chair, Expert Reference Group, National Service Framework for Long-term Conditions

Executive summary

MS is a challenging disease to live with. It is a long term and unpredictable condition and individuals can experience acute relapses. In order to provide responsive services health professionals must find out what people with MS want, agree best practice and work collaboratively within a framework of robust evidence. This document is designed to share some examples of best practice in relapse management across the UK and provide useful, practical information on patient focused services that can then be adapted to meet local needs.

Key background papers and models of care

Benchmark, audit & research

MS nurses are well placed to deliver high quality patient care. In addition to the clinical component of the role MS nurses must lead on service development using research, consultancy, and leadership skills within a philosophy of collaboration. Some examples of these skills are given in the next sections

1. Benchmarking of best practice in relapse management by **The Midlands MS Nurse Group**.

   This group was the first in the UK to systematically challenge how relapse management was delivered in their local region. A benchmarking process was used to provide a quality driven service. This process allowed identification of quality outcome measures in service provision and sharing best practice examples through collaboration. Although this strategy resulted in a document outlining good practice it did not translate into organisational change immediately. However, the work did provide a platform for further development of local strategies and a number of improved services have since evolved.[1]

2. Building on the benchmarking project **Richard Warner and colleagues** completed an action research project. The project was completed over 18 months within a district general hospital population.

   They completed an action research study over an 18 month period in a district general hospital population. In the period prior to the research the majority (88%) of local people with MS had to wait more than 10 days to receive treatment. The action research study facilitated the team of MS nurses and neurologists to change their service from an inpatient model to an outpatient and day case service. The study improved the quality of service provided, the team have since identified and treated a three fold increase of patients, 85% of whom are seen and treated within 10 days.[2]

3. Relapse management transformation by **Bernadette Porter and the Queen Square Clinical Services MS Group**.

   This multidisciplinary group used audit to explore treatment pathways in a large tertiary referral service. The audit process identified unacceptable delays and provided objective evidence to support the need to implement change. As noted in other settings the audit demonstrated that patients were admitted to a neurological inpatient day units experienced long delays to receipt of treatment. In this case the mean delay was 6.1 weeks. The team used a pilot study of an outpatient service to test change and identify potential problems. The pilot study provided a solid evidence base in which to modernise and change existing service provision. The study demonstrated safe administration of IV steroids in an outpatient department and reduced mean response times to 6 days.[3]

   However, the outpatient model requires the patient to visit hospital when they are feeling least able. In order to address this issue, the team undertook a literature search for evidence in support of a home delivery service model. There was no evidence to support a home care delivery model in MS. In addition, there were no outcome measures to assess what people deem important in management of MS relapses. In order to examine this area the team were successful in obtaining a grant from the MS Trust. The first stage of research was to create a psychometrically robust outcome measure. The second stage involved the completion of a randomised controlled trial of 138 patients comparing outpatient versus home delivery of steroids. The trial demonstrated that ultimately a home based service is superior from the patient's.[4]

Models of care

Management of an acute relapse requires a comprehensive approach addressing its medical, functional, and psychological effects. Management incorporates education regarding relapses, support in the event of a relapse, treatment to accelerate or improve the recovery for a relapse and symptomatic treatment and rehabilitation.[5]

People with MS are often expert in detecting and anticipating changes in their health and wellbeing. Health and social care professionals should support people with MS to become expert patients by aiming to give the person the knowledge, skills and confidence to participate actively in all aspects of their own care.

People are not passive recipients of prescribing decisions. They have their own views about medicines, how they should be used and how medicine taking fits in with their daily lives. These views are based on a personal set of beliefs and understanding influenced by factors including the experience of family and friends, culture, education and social circumstances. They may be based on an incomplete understanding of the nature of the illness and the proposed treatment or at odds with scientific evidence. In other cases they may be based on a patient's own experience of medicine taking and their

knowledge about what fits in with their lifestyle. Studies of doctor-patient communication suggest that these beliefs and views are not often explored in prescribing consultations. Studies have shown that doctors underestimate the degree to which they 'instruct' and overestimate the degree to which they 'consult' and elicit patient's views.

Research, surveys and people's individual stories have shown that people are making conscious decisions about whether to take medicines based on their views, beliefs and experiences. People are therefore more likely to benefit from therapy when they understand the diagnosis and treatment, have had a chance to discuss their views and beliefs and are actively involved in decisions about management of the condition. It is increasingly recognised that the key to making better use of medicines is involving people as partners in decisions about their medicines - sometimes described as concordance. Concordance is a new way for prescribers and patients to agree about medicines together

Corticosteroids are the mainstay of treatment for disabling relapses. The Cochrane review demonstrated that for every 100 patients treated with steroids, 25 more patients improve compared to placebo (95% CI 14-35).[6]

Treatment of MS relapse with steroids is well accepted worldwide however treatment practices vary in clinical settings.

A **European task force** (EFNS) reviewed the literature to provide evidence-based treatment recommendations

The group concluded that because of the low number of patients included in oral versus intravenous clinical trials completed to date that efficacy differences between the routes cannot be excluded. The reviewers state that the optimal dosage, the specific steroid to be used and whether or not to use a taper after initial pulse therapy, has not been adequately addressed in randomized control trials. The task force suggest that there is a need for new, randomized studies assessing risk/benefit ratios and adverse effects for specific types of steroids, dose and route of administration.[7]

The National Institute of Clinical Excellence (NICE) states that any person who experiences an acute relapse (including optic neuritis) sufficient to cause distressing symptoms or an increased limitation on activities should be offered a course of high-dose corticosteroids starting as soon as possible after onset of the relapse and should be either:

- intravenous methylprednisolone at a dose between 500 mg and 1 g daily for between 3 and 5 days

  or
- high-dose oral methylprednisolone 0.5 g - 2.0 g daily) for between 3 and 5 days.

People with MS should be counselled on the risks and benefits involved (see evidence statements and tables in the full guideline for details). Frequent (more than three times a year) or prolonged (longer than 3 weeks) use of corticosteroids should be avoided.

The NICE guidelines acknowledge the need for a multidisciplinary approach to optimize relapse management. **The Walton Centre** has demonstrated through the work of **Jenny Craig** that planned MDT assessment and intervention combined with intravenous steroids for 3 days had superior beneficial effects compared to standard administration of IV steroids.[8]

The potential roles of team members in relapse management are outlined in an additional section however team members and roles may vary to reflect local needs and resources.

The NICE guidelines recognizes that an acute episode will usually cause some increased limitation on activities, and the increased disability will itself often require urgent intervention, if only the provision of additional support to the person with MS. The guidelines suggest that involvement of neurological rehabilitation services should be in parallel with any medical treatment needed:

> When a person with MS experiences a sudden increase in disability or dependence the individual should be:
>
> - given support, as required and as soon as practical, both in terms of equipment and personal care
> - referred to a specialist neurological rehabilitation service. The urgency of the referral should be judged at the time, and this referral should be in parallel with any other medical treatment required. [9]

Clinical governance considerations
The administration of oral or intravenous steroids for the treatment of MS relapse must be conducted within a framework of clinical governance. Clinical governance can be defined as 'a framework through which NHS organisations are accountable for continuously improving the quality of services and safeguarding high standards of care be creating an environment in which excellence in clinical care will flourish'

In order for the pillars of governance to flourish, it is fundamental that the foundations of clinical governance are strongly embedded in clinical practice**.** The clinical and management team must have a clear vision with strong leadership and creativity. Clear communication and effective teamwork must be present to ensure success. Teams must be clear of their philosophy, and in working towards this they must remember to adhere to evidence based practise guidelines working within professional boundaries.

The Kings College Hospital group led by Pauline Shaw have developed an excellent example of a clinical governance protocol for the administration of oral steroids in the community including information for GPs.[10]

Emily Harrison has adapted the Queen Square pathway for administration of intravenous steroid in the community for Islington Primary care Trust.[11]

An integrated care pathway
The Queen square team have developed an integrated care pathway (ICP) for relapse management.[12]

An ICP is a multidisciplinary outline of anticipated care, set within an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes. The Queen Square ICP uses multidisciplinary guidelines to develop and implement clinical plans, which represent current local best practice. The ICP also incorporates national guidelines, evidence-based practice and benchmarking.

The ICP forms part of the clinical record, and in some cases it replaces other forms of documentation, such as nursing care plans. While patients' progress follows the pathway, the appropriate health professional signs for the care he/she has delivered. If the patient's care or progress varies from the pathway it is recorded as a variance, together with the reason and the action that has been taken. Members of the team can choose to deviate from the pathway but this must be clinically justified, e.g. deterioration in the patient's condition or intolerable side-effects. This encourages staff to adhere to the guidelines specified on the pathway, thus reducing variations in the care provided. ICPs allow innovative and creative ways of improving quality of care, and for quality assurance to flourish.

Tele triage
In the event of new or increased symptoms people with multiple sclerosis should be able to identify and contact a professional from their healthcare team who can advise them or direct them to the most appropriate local service. Often, the health professional needs to obtain information and clinically assess the individual over the telephone.

In addition to competence in clinical assessments specialist nurses must develop specific telephone communication skills which differ significantly from face-to-face interactions.

Tele-triage skills
- Active listening & detailed history taking
- Frequent clarifying & paraphrasing (to ensure that messages have been understood in both directions)
- Picking up cues (such as pace, pauses, changes in voice intonation)
- Offering opportunities to ask questions
- Offering advice and information
- Documentation

Specialist MS nurses can use expert clinical assessment skills to screen patients appropriate for clinics and those who require other areas of support

and treatment within the locality. Clinical assessment questions can be developed into a clinical care pathway document to help standardise the approach to evidence based practice. The Queen Square ICP begins at tele-triage.

An adaptation of this model to create a Relapse 'head to toe' prompt sheet has been developed by Medway Kent.[13]

Assessment and treatment of Urinary Tract infections

People with MS may have asymptomatic urinary tract (or other) infections. Practice varies across the UK on whether or not steroids should be used in the presence of a urinary infection. Fiona Matheson and Jeremy Chataway of the Queen Square group have worked with hundreds of people with MS and microbiology colleagues to design a clinical algorithm to guide treatment options and inform best practice.[14]

Advanced practice

Many clinical nurse specialists work as advanced and autonomous practitioners who are competent, accountable and responsible for their own practice. The experienced MS nurse will use extended skills in making a differential diagnosis, screening for concomitant disease, developing preventative care management programmes and referring or discharging patients. Some examples of this are:

Nurse led MS relapse service delivered by Megan Burgess at Salford Royal Hospitals .In this model the Nurse Consultant leads the assessment, treatment and follow-up of relapse patients using a patient group direction to direct nurse prescription of treatment.[15]

Non medical prescribing specialist nurses. Nikki Embrey and Claire Lowndes from University Hospital North Staffordshire and North Midland Regional MS centre provide enhanced levels of patient care with a reduction in delays to treatment.[16]

Other examples include

Megan Burgess' plan for a new nurse led clinical relapse service.[17]

The joint Queen Square / Islington PCT community Inreach / Outreach service.

Summary

MS is a dynamic disease requiring responsive appropriate management. The needs of individuals will vary, local practice will reflect available resources but should always be evidence based. It is hoped that this Key Steps resource will help UK health professionals design and deliver models of care fit for the 21st century.

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Bernadette Porter, Fiona Matheson, Jeremy Chataway and others.
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