This is a digest of selected articles published in peer reviewed journals over the last quarter relevant to health and social care professionals working to support people with MS.

Where the full text of the article is available for free, a TinyURL which links directly to the full article is provided.

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### Disease modifying treatments

**Robles-Sánchez MA, Porter B.**
The role of the MS clinical nurse specialist in the management of disease-modifying drugs.

Overview of disease modifying drugs currently available in the UK and the role of the MS specialist nurse in patient education, supporting self-management, building relationships with patients and expert understanding of shared decision making. Highlights the conditions that should be in place for shared decision making in this complex arena as; ready access to information about treatment options, guidance on how to weigh up the pros and cons of a treatment, and a supportive culture that enables engagement.


### Diagnosis

**Filippi M, Rocca MA, Ciccarelli O, et al.**
MRI criteria for the diagnosis of multiple sclerosis: MAGNIMS consensus guidelines.

Guidelines provide an evidence-based and expert opinion consensus on modifications to MRI criteria for diagnosis of MS. These proposed revisions to the 2010 McDonald criteria include; using identical criteria for dissemination in space for diagnosing primary progressive and relapsing onset MS; imaging the whole of the spinal cord to define dissemination in space (especially where people do not fulfil brain MRI criteria); including lesions of the optic nerve as an additional CNS area; requiring no distinction between symptomatic and asymptomatic MRI lesions in time or space. Authors conclude that a conservative approach to lesion identification should be used, that this should be carried out by expert personnel and that image quality should be of a high standard. They also note the FDA concern of the long-term effects of repeated use of gadolinium-based contrast agents for MRI.


The communication of multiple sclerosis diagnosis: the patients’ perspective.

Single centre observational study that included 150 consecutive people who received a diagnosis of clinically isolated syndrome or MS at a neurological centre. Patient satisfaction with the communication of diagnosis was assessed using a questionnaire survey which included questions on information provided, their reaction, emotional profile and view of communication issues. These were recorded on a scale of low, medium or high. 75% of participants reported moderate or high satisfaction with the communication process and information provided. The most important factors influencing patient satisfaction were found to be tailored information provision and adequate emotional support. Authors highlight the importance of a good communication experience at diagnosis in acceptance of MS and subsequent treatment compliance.

*Mult Scler Int* 2015;2015:353828. [Ref 20-2-3]

http://tinyurl.com/QMSRU-20-2-3
Relapse

Tallantyre EC, Wardle M, Robertson NP.

How to run a multiple sclerosis relapse clinic.

Considers service model for an open, rapid-access relapse service as recommended by the NICE MS Guideline. Considers the benefit of allied health professional input in providing acute intervention and promoting interdisciplinary learning within the MS team against rapid access to multidisciplinary neurorehabilitation. When to use high dose corticosteroids and current lack of consensus of treatment regime are addressed along with the key patient education required. 70% of those presenting to the service described who were designated as non-relapsing received either change of symptom management medication or referral to therapy. The opportunity to review instigation of disease modifying drugs, switching or stopping therapy are addressed along with the key patient education required. Potential pitfalls highlighted include overuse by certain clients.


Pregnancy and childbirth

D’Amico E, Leone C, Patti F.

Offspring number does not influence reaching the disability’s milestones in multiple sclerosis: a seven year follow up study.

86 women with MS were included in this retrospective study and of these 65% had one pregnancy after the onset of MS whilst the remainder had more than one pregnancy after MS diagnosis. The number of women who breastfed their children was not significantly different in both groups. During the seven year follow up period researchers measured the time it took women to reach EDSS 4 and EDSS 6. There was no significant difference in the groups to reaching disability milestones and authors state that it is therefore unlikely that number of children has an influence on the long term prognosis for women with MS.


Self-management


Variables associated with patient activation in persons with multiple sclerosis.

199 people with MS, 163 of whom were women, completed a number of questionnaires; Beck Depression Inventory, Patient Activation Measure, MS Self-Efficacy Scale, and the Leeds MS Quality of Life Measure, at routine MS centre visits. Quality of life was not related to patient activation but depression was a key factor. Educational level was also associated with patient activation and authors suggest that this is likely to be linked to health literacy, postulating that low levels of health literacy in MS, may mean people have more difficulty understanding and complying with treatment. Areas where intervention may result in increased patient activation including health literacy and depression management are suggested as key targets for health professional input.

J Health Psychol 2016;21(1):82-92. [Ref 20-2-6]

Falls

Hugos CL, Frankel D, Tompkins SA, et al.

Community delivery of a comprehensive fall-prevention program in people with multiple sclerosis: a retrospective observational study.

Self-report evaluation of the MS-specific Free From Falls (FFF) programme from the National MS Society of America. 109 people completed the programme that comprised eight sessions of one hour exercise and one hour fall prevention education. After six months on the FFF programme fewer falls were reported, balance confidence and functional mobility increased. 12% of participants became non fallers compared to base line. Authors suggest that FFF may reduce risk of falling for people with MS and that larger randomised controlled trials should be carried out.


Symptoms

Broune C, Salmon N, Kehoe M.

Bladder dysfunction and quality of life for people with multiple sclerosis.

19 people with MS took part in an interview study where they discussed their experience of living with bladder problems and their impact on daily life. Participants reported that bladder problems had disrupted their lives, interfered with activities such as sleep, travel and sexual relationships. Some also felt they had lost control, security and enjoyment of events. Many participants believed that bladder symptoms were an unavoidable result of MS and health professionals had nothing to offer. All participants had learned which actions made their bladder problems worse and described how they had managed through a ‘trial and error’ approach. The authors highlight the need to raise awareness of the general and specialist help available to people with MS to manage continence problems and make available information about self-management of bladder symptoms for people too embarrassed to ask for help.

**Vitamin D**


Safety and immunologic effects of high- vs low-dose cholecalciferol in multiple sclerosis.

40 people with relapsing remitting MS received either 800 IU or 10,400 IU of vitamin D3 (cholecalciferol) every day for six months. Blood tests were performed before the study started, after three months and six months. Levels of vitamin D in the blood increased more for the participants taking the higher dose and appeared to be immunomodulatory, as levels of markers for certain T-cell types involved in MS disease activity changed in the high dose group but not in the low dose group. Authors suggest the results show that vitamin D may modulate the immune system activity associated with MS but larger studies are required.

Neurology 2016;86(4):382-90. [Ref 20-2-10]

**Family**

Bogosian A, Hadwin J, Hankins M, Moss-Morris R.

Parents’ expressed emotion and mood, rather than their physical disability are associated with adolescent adjustment: a longitudinal study of families with a parent with multiple sclerosis.

58 families took part; the sample comprised 56 parents with MS, 40 partners without MS and 75 adolescent children aged between 12 and 19 years. Parents completed questionnaires to explore anxiety and depression, EDSS and the Five Minute Speech Sample test to assess expressed emotion towards their child. Adolescents completed a self-report measure of psychological difficulties. Both groups completed the same set of questionnaires at base line and six months. Authors conclude that emotional distress and expressed emotion in parents with MS, rather than MS severity, impacted on psychological difficulties for adolescents.


Illness perception and well-being among persons with multiple sclerosis and their caregivers.

68 people diagnosed with relapsing MS >10 years and moderate disability, and their caregivers answered questionnaires exploring illness perception, wellbeing, life satisfaction and positive or negative affect. In both groups wellbeing was positively associated with understanding of MS and inversely associated with negative emotions. Authors suggest that practitioners could include both reduction of distress and negative illness perception alongside wellbeing promotion. Interventions that also involve caregivers could also improve mutual understanding about which areas of illness are more important to each individual.


**Quality of life**

Lysandropoulos AP, Haardova E, ParadigmMS Group.


Review examines the impact of cognition, fatigue, isolation, sexual dysfunction, family dynamics, relationship issues and the inability, or reduced ability, to work on quality of life for people with MS. Authors suggest that quality of life measures that capture these symptoms, are a more relevant outcome measure for people with MS than measures of disability progression or neurological impairment. Shortcomings of current quality of life measures and lack of validation are considered.


**Mortality**

Manouchehrinia A, Tanasescu R, Tench CR, Constantinescu CS.


12 studies were included in the review which comprised data from 28,706 people in which 6,628 deaths occurred. Death due to cardiovascular disease, suicide and infection was found to be higher in people with MS compared to the general population. Authors note that excess mortality in MS relative to the general population has not changed over the past 50 years.

J Neurol Neurosurg Psychiatry 2016;87(3):324-31. [Ref 20-2-14]

**Employment**

Cadden M, Arnett P.

Factors associated with employment status in individuals with multiple sclerosis.

Study of 53 people with MS (8 men and 45 women), 30 with relapsing remitting MS, 17 with secondary...
progressive, three with primary progressive MS, and three with progressive relapsing MS. 33 of the participants were employed at the time of the study. Cognitive, motor function and fatigue test scores, as well as higher EDSS scores, were significantly related to unemployment whilst levels of depression were not. Fatigue, slowed processing speed and memory difficulties were particular problems when trying to remain in employment. Researchers suggest that health professionals can support people to find effective management strategies to deal with, or compensate for, fatigue and cognitive symptoms which could aid employment retention.

http://tinyurl.com/QMSRU-20-2-15

Work-related problems in multiple sclerosis: a literature review on its associates and determinants.

42 studies from 1993–2015 were included in the review, comprising 31,192 people with MS, 75% of whom were women. 18 variables were found to be associated with change in the course of work related difficulties including MS duration, age at onset, EDSS, progressive course, fatigue, cognitive functions, mobility, walking and problems with activities of daily living. Authors suggest that many of these factors are amenable to rehabilitative intervention and their impact on vocational outcomes should be addressed.

Disabil Rehabil 2016;38(10):956–44. [Ref 20-2-16]

Exercise

Lindroth JL, Sullivan JL, Silkwood-Sherer D.
Does hippotherapy effect use of sensory information for balance in people with multiple sclerosis?

Case studies that explored changes in sensory processing for postural control in individuals with MS using hippotherapy (HPOT). Three participants took part in twelve 40 minute physical therapy sessions which included HPOT twice a week for six weeks. Sensory organisation, balance and gait were assessed prior to therapy. All participants showed improvement at the end of the intervention and at follow up in all domains. Authors suggest that this demonstrates HPOT may be a beneficial treatment strategy to improve balance, functional gait and enhance postural control for some individuals with MS but will require RCT to validate results.

Physiother Theory Pract 2015;31(8):575-81. [Ref 20-2-17]

Outcome measures

Defining reliable disability outcomes in multiple sclerosis.

The disability outcomes used in many clinical trials rely on progression according to the Expanded Disability Status Scale score (EDSS) confirmed over three or six months. Researchers used the global MS Base cohort of over 16,000 people with a minimum of three recorded EDSS scores and found the most important determinant of progression stability was the length of the confirmation period. Measuring symptoms for 12 to 24 months was found to be more accurate in determining confirmed events persistent over 5 years. Improvement post-progression was more common in younger people, those with RRMS, and where there had been a smaller change in disability. Authors state that these results suggest that the disability outcomes based on three to six months confirmed disability progression overestimate the accumulation of permanent disability, and this could be by as much as 30%.

Brain 2015;138(11):3287-98. [Ref 20-2-18]

MS services

Nurse led telephone assessment of expanded disability status scale assessment in MS patients at high levels of disability.

Multi-centre single-blind trial of 90 people all with EDSS >6, 15 with primary progressive MS, 74 with secondary progressive and one with relapsing remitting MS. EDSS level was assessed both by an MS nurse on the telephone using a questionnaire and by an experienced neurologist in a face to face neurological assessment. Prior to the study, nurses received training from the physicians on use of the questionnaire. Authors found that nurse led telephone assessment of EDSS was accurate within 0.5 EDSS point of the face to face clinical assessment. Consequently they conclude that this can provide a valuable tool where patients are unable to attend appointments and may also maximise retention in long term studies.


Quinn D.
Succession planning: who can follow on from you?

Focusing on specialist practitioners, the author underlines the importance of planning for your own exit, which also requires commitment from the team and senior management. Considers how analysis of the post, team strengths, recognition of team members who could be developed, critical skills required for the role, and the skill gaps within the team are key. Author also highlights the necessity for regular review to allow for adjustment to changing demands, and stresses the strong leadership that is fundamental to ensuring high quality talent and services are developed and maintained.