

Lost to Follow up : What are the implications.

Y Jagatsinh, B Chandler, J Metcalfe, H Hunter

MS Team, Berwick upon Tweed. Northumberland.

E-mail: dryogen@gmail.com • phone: 0191 287 5194



Introduction

Multiple Sclerosis (MS) is very variable for an individual. Changes may occur due to relapse, slow progression or as a secondary consequence, e.g. musculo-skeletal problems resulting from poor posture. If there is no regular review how are problems dealt with?

Specialist neurological and neurological rehabilitation services should be available to every person with MS, when they need them. This need may arise because of new symptoms, problems of function, or when circumstances change³.

People with MS (PwMS) in Northumberland felt disadvantaged because of long distances to specialist advice and support (Edinburgh and Newcastle - 70 miles away). Co-ordinated service planning should ensure that suitable services are available within a reasonable travelling distance; this may involve the establishment of satellite services or peripatetic teams to reach isolated locations.

Difficulty of accessing services because of distance resulted in people in this area often having no contact with neurological services after the period of diagnosis and the initial interventions.

Results

There have been 29 service users from Northumberland and 10 from the Scottish Borders. Twenty nine patients had problems requiring treatment and/or referral. Patients and carers valued the opportunity to discuss problems with the health professionals. Following the discussions appropriate referrals were made as necessary. The problems which were picked up were bladder dysfunction, trigeminal neuralgia, musculoskeletal pain and stiffness, mobility and posture, social issues. The Table shows the number of referrals made to different parts of health and social care.

Referrals following contact in out-reach service

Referral to	Number of Patients
Consultant	3
MS Nurse	11
MDT Review	1
Continence Review	1
Neuro-physiotherapy	15
Social Services	1
General Practitioner	3
Community Rehab Team	5
Podiatry	1



Discussion

All services and service personnel within the healthcare sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively in all decisions and actions³.

Many of the patients attending the out-reach service had no regular follow up and had simply "got on with things" not realising that help might exist for symptoms. If unaware of services people do not seek help.

People struggle with problems that can be treated e.g. continence, mobility and pain. Follow up must be accessible and available locally. Health care professionals can "sign post" these patients to an appropriate specialist.

The recent Lord Darzi review has emphasised the importance of appropriate services which are available to all patients².

Conclusion

- We have shown that people can be lost to follow up and struggle with a variety of symptoms and problems.
- PwMS in regular contact with health care professionals can review 'hidden' problems contributing to their clinical situation, such as fatigue, depression, cognitive impairment, impaired sexual function or reduced bladder control.
- Every person with MS who has been seen by a specialist neurological or neurological rehabilitation service should be informed about how to make contact with the service when he or she is no longer under regular treatment or review. The individual should be given guidance on when such contact is appropriate³. By allowing informal, patient led contact with this out-reach service PwMS have had the opportunity to link back into a review system according to their individual needs. The service is local, responsive and in keeping with NICE³, NSF (LTC)⁴ and the Lord Darzi review².

References

1. Outreach MS Services, J Metcalfe et al : Poster MS Society Professional Network, Wetherby 2008.
2. High Quality Care for all. NHS Next Stage Review Final Report, HMSO 2008.
3. NICE Guideline- Multiple sclerosis. Clinical Guideline 8, November 2003.
4. NSF for Long Term Conditions 2005