

Introduction

This paper describes the importance of identifying disease transition points early for people affected by multiple sclerosis. It also supports the access to appropriate and early supports that will be responsive to the specific needs of the individual. This will ultimately reduce and / or delay the need for, and cost of, future or longer-term supports through 'Early Intervention'.

We offer the two definitions below as being consistent with the thinking of 'early intervention' by NDIS while being relevant for adults living with disability as a consequence of acquired and progressive disease; where the functional impact fluctuates and changes are unpredictable.

- *Early intervention is the process of providing specialist intervention and support services for a person who needs them, either early in the life course, and/or early in the development of an issue or problem. The term may be used in slightly different ways across different sectors.*
www.responseability.org/_data/assets/pdf_file/0006/4866/Early-Intervention.pdf
- *Disability Management is a relatively new field and is defined as "an active process of minimizing the impact of impairment on the individual's capacity to participate competitively in the work environment" (Shrey & Lacerte, 1995, p.5). Central to the practice of Disability Management is the concept of early intervention and a focus on psychosocial issues (Dyck, 2000).*
www.ijdc.ca/VOL02_02_CAN/articles/harder2.shtml

Purpose

The purpose of this document is to invite NDIS to partner with the state and territory Multiple Sclerosis Societies, to facilitate a consistent approach to the identification of people with multiple sclerosis best placed to receive early interventions support funded by NDIS. In addition, to collect and provide evidence that identifies the types of supports that will reduce or alleviate the burden of significant impairment related to their fluctuating neurological disorder.

About multiple sclerosis

Multiple sclerosis is the most common acquired neurological disease diagnosed in young adults, with the majority of people being diagnosed between 20 and 40 years of age. The onset and experience of the disease varies greatly from individual to individual; and for many people the impairment and the resulting disruption impacts on areas such as family roles/relationships, employment and daily functioning.

The impact of the disease on individuals, their families and the community can undermine the resilience that is needed for individuals to remain purposeful and in control of their lives. The characteristics of this disease can threaten the sustainability of employment, friendships, social interactions and partnerships and many relationships fail; thus causing further isolation, depression and an increased reliance on social services.

What we know through studies, pilot projects and literature is that relevant interventions that consider the individuals personal and social context, in relation to their functional impairment, are required at each disease transition point across the lifelong journey. When people with multiple

Early Intervention for Adults with multiple sclerosis

sclerosis are seeking access to the scheme, there is a need for mechanisms that will assist individuals and NDIA planners to recognise the common silent, invisible symptoms that can manifest in significant functional impairment.

Hidden symptoms such as fatigue, blurred vision, poor memory and thinking, fluctuating mood, reduced strength and sensation can impact on emotional wellbeing and physical functionality. For example fatigue is recognised as the most commonly reported neurological symptom of multiple sclerosis; with up to 80% of people experiencing this debilitating symptom (Simmons et al. 2010). Fatigue can impact on mobility, mood, thinking, memory and in turn impact on functionality such as working, taking children to school, attending appointments amongst other family and social activities. Fatigue can also significantly impact on a person performing everyday tasks such as preparing a meal, attending to personal hygiene, domestic chores and maintaining employment.

Supporting research

The Australian MS Longitudinal Study (AMSLS) Economic Impact working party in 2010 reported 49% of people with multiple sclerosis reported leaving paid employment specifically as a result of multiple sclerosis. The common reasons reported as contributing to loss of employment were a combination of the disease related symptoms, environmental and social factors. The main symptoms cited were fatigue (79%), physical problems with legs or feet (47%), arms or hands (41%); balance problems, brain fog and continence were also reported. Other barriers to remaining in work or placing employment at risk included but are not limited to : architecture of the work place, being able to more safely move around the workplace, getting to and from work, not being able to concentrate due to fatigue and 'feeling I am not doing a good enough job'. This study identified that the impact of loss of paid employment went beyond financial hardship but resulted in poor self-esteem and had significant implications for families, friends and relationships. Without tailored early interventions, either before people give up employment or soon after, the impact becomes wide ranging and includes welfare dependency. The study also reported that 40% of working age people with multiple sclerosis are recipients of the disability support pension (Australian Population: 5%).

The level of functionality of the individual can change depending on the impact and interplay of symptoms. People can often experience significant fluctuation and exacerbation of their symptoms within short time periods, so they can experience more challenges on one day compared, to another or even fluctuations within a day.

Benefits of early intervention

Understanding these issues, and the benefit of timely implementation of the right intervention is likely to allow for enhanced quality of life outcomes; including maintaining economic independence, and social interactions for as long as possible.

Examples of interventions may include:

- Assessment by an experienced neurological-physiotherapist to identify impairments of strength, balance and reduced sensation; making recommendations for individualised exercise programs, prescription of walking aids and management of pain
- Assessment by an experienced Occupational Therapist to identify goals and develop individualised strategies to maximise independence and achieve desired outcomes.
- Assessment by a Specialist Employment Support Service to address work needs/aides to maximise the opportunity to remain in work. These can include the planning and

Early Intervention for Adults with multiple sclerosis



management of work, home and community tasks and activities, initiating and attending appointments, engaging socially to remain connected to family and friends, and being able to contribute positively and meaningfully in social valued roles.

Critical to individuals having choice and control, are targeted, timely supports such as: home/domestic help, community and civic supports, psychological and emotional support and assistance with coping with life transitions and adjustment. These can assist with minimising the impact of impairment caused by a debilitating and commonly occurring symptoms such as fatigue and mood fluctuations; and maximising opportunities and independence.

Conclusion

A collaborative approach with NDIS and willingness to share our collective experience offers the opportunity to identify timely supports and interventions that can facilitate people to have the increased capacity to plan ahead, maintain employment and remain as independent as possible for as long as possible.

We believe there is significant cost to the individual over a lifetime and reasonable evidence to support the need to establish a stronger evidence base for timely and targeted funded supports; and early on in the person's disability/impairment.

References

- Rex Simmons, Kate Tribe, Elizabeth McDonald (2010) **Australian MS Longitudinal Study (AMSLS) Economic Impact working party in 2010**

This is a survey based platform that, over the last ten years, has built up a cohort of over 3,000 people with multiple sclerosis. These committed individuals complete regular surveys, at least one per year, on a range of topics and issues of practical importance to people with MS. This enables a truly longitudinal analysis of outcomes for people with MS and an accurate assessment of the factors that impact on those outcomes.

The AMSLS cohort has recently been validated as being highly representative of the Australian population of people with MS (Taylor et al, 2013, *Mult Scler.* 2013 Mar 25).

The AMSLS has already gathered a large body of baseline data on quality of life, economic impact, needs (met and unmet) and employment. Data from the AMSLS has been instrumental in advocating on behalf of people with MS for better services, benefits and research.

- Ceri Bowen, Anna MacLehose, (2010) "Multiple sclerosis: long-term social care and the 'family care pathway'", *Social Care and Neurodisability*, Vol. 1 Iss: 1, pp.31 – 38
- Community health counselling: Policy framework and program standards, Primary Health Branch, Victorian Government Department of Human Services, Melbourne Victoria, February 2009

Early Intervention for Adults with multiple sclerosis



- Chiu, C. et al, (2013), “State vocational rehabilitation services and employment in multiple sclerosis”, Multiple sclerosis, 2013, 19 (12):1655-64
- Flensner et al, (2013), “Work capacity and health-related quality of life among individuals with multiple sclerosis reduced by fatigue: a cross-sectional study”, BMC Public Health, 13:224

Case studies

These evidence enhanced quality of life through early interventions

Demographics	Situation Context	Interventions Implemented	Outcome resultant of intervention
Working people, or young mums, with MS with low support needs but impacted significantly by fatigue	Employment at risk, or risk of being unable to cope at home, due to fatigue impacting on ability to function fully.	<p>OT advice and education on self-management of fatigue</p> <p>OT workplace assessment and suggestions on managing and banking energy</p> <p>Advocacy with employer around ergonomics & situation; may include reduced hours</p>	<p>Greater understanding of their fatigue and self-management strategies</p> <p>Recommendations on ergonomics of the workplace and processes of work</p> <p>May include recommendations such as relocation of office closer to front of building, downstairs vs upstairs etc.</p> <p>May include reduced hours or structured breaks for rest during the shift etc.</p>
Working people, or others, with continence issues	Employment / socialisation at risk due to concerns re continence in the workplace and socially	<p>Continence / MS nurse assessment, advice and strategies</p> <p>OT workplace assessment and intervention with assessment re access to toilets</p> <p>Information and advice re location of toilets etc. in the community to build confidence</p>	<p>Improved bladder and or bowel management</p> <p>Improved access to toilets in the workplace</p>

Early Intervention for Adults with multiple sclerosis



<p>34 year old female, married with 3 children. Client's primary role is caring for the family and maintaining the home. Has RRMS but also recently diagnosed with anxiety & depression</p>	<p>Husband works 60 hours a week in order to meet the family's financial commitments. Since her Multiple Sclerosis has progressed, the client no longer has the energy to keep up with the chores beyond daily meal preparation and dishwashing. This has significantly impacted on her health and is a large contributor to her recent mental illness diagnosis. Client was feeling "useless" and "a burden" to her husband who had no time to help with the extra chores.</p>	<p>Client not deemed "disabled" enough to be eligible for HACC or state Disability Services.</p> <p>MS provided client with counselling and ongoing assistance with cleaning.</p> <p>Client also referred to MS physio for advice on managing fatigue.</p>	<p>This has provided client and her husband valuable time to spend together with their family. In Client's words, "The support is fantastic! The change it has made to my family is enormous. I now even have the energy to get to my physio appointments so I can learn new ways of managing my fatigue. With my extra energy, the kids think they have a new mum!"</p>
<p>J is a male in his 40's and is passionate about work in customer service in a busy call centre</p>	<p>J works in a busy call centre, his employment is important to his social, emotional and financial wellbeing. J is a valued member of the team however muscle fatigue was impacting his productivity and mobility, safety in moving around the office (falls risk)</p>	<p>Implementation of a software program that limited the number of clicks when J was using his computer</p> <p>Assessed for a scooter</p>	<p>J maintained his employment, Work place affirmed J as an important member of the team. Moved around the office safely, reduced falls risk and managed fatigue</p>