Getting The Balance Right

A nationwide exercise-based, health-promotion and research programme for people with Multiple Sclerosis

Summary Findings
September 2009
GETTING THE BALANCE RIGHT PROGRAMME OVERVIEW

In 2006, MS Ireland conducted research among its members relating to services for people with MS. (Lansdowne Market Research). The findings clearly highlighted that physiotherapy and exercise related programmes were the top priority of services required but not widely available either through the HSE or from MS Ireland, due to the current level of resources.

A number of studies have looked at the benefits of physiotherapy and exercise related activities for people with MS. The literature suggests that a range of exercise programmes with wide-ranging durations and intensities all have positive effects on the functional abilities and participation levels of people with chronic diseases, however rates of participation in regular exercise is lower in people with MS. (Motl et al 2005).

With the need identified and benefits demonstrated, MS Ireland, in conjunction with the University of Limerick, developed a programme to respond to this need through physiotherapy and exercise-based interventions.

Getting the Balance Right is MS Ireland’s nationwide exercise-based, health-promotion and research programme for people with Multiple Sclerosis. The aim of the programme is to give people with MS the opportunity to access physiotherapy and exercise related interventions at a pace and place suitable to the person’s need. It is also an opportunity to profile people’s needs and assess the benefit of interventions, allowing us to provide and advocate for better services for people with MS.

THE PHYSIOTHERAPY AND EXERCISE PROGRAMME

To date, 1,652 people have taken part in the many varied physiotherapy and exercise related activities such as group and one-to-one physiotherapy, yoga, instructor led gym classes, tai-chi and hydrotherapy. Each of these interventions was, and continues to be, delivered locally in towns and villages across the country. Typically, each programme lasts 10 weeks.

Each participant on the programme receives an assessment by a Chartered Physiotherapist, which measures a range of physical and psychological elements. This process divides people into three distinct strands allowing participants to access interventions with those of similar ability. Strand A participants are those who use a walking stick or crutch. Stand B participants are those who use bilateral aids such as a rollator or two sticks/crutches. Stand C participants are wheelchair users.

Overall we estimate that 16,520 separate intervention sessions took place over the course of the programme.

* Numbers may vary slightly due to the ongoing nature of the programme
THE RESEARCH PROGRAMME

Getting The Balance Right research programme was a stratified, single blind, randomised, controlled trial coordinated by The Physiotherapy Department of The University of Limerick. Ethical approval was obtained from 11 ethics committees nationally. All participants received an assessment by a Chartered Physiotherapist to ensure safety and suitability.

503 people took part in the research element through the various physiotherapy and exercise programmes. They were grouped according to their mobility and randomised to various programmes e.g. one-to-one physiotherapy, group physiotherapy, yoga and fitness instructor led gym sessions. Each person was assessed before and after their normal 10 week programme and again 10 weeks after the programme finished.

76 people took part in the research as controls and did not alter their usual activity. Once they finished their control period participants were offered the physiotherapy or exercise-based programme of their choice.

SOME KEY FINDINGS:

- The average duration of current physiotherapy intervention in a variety of settings is three hours in a three month period.**
- 23% of the total number of people who at most use a stick improved their level of fatigue to the extent that they moved them from a clinical measurement of ‘fatigued’ to ‘non-fatigued’. This was reported in 27% of those on physiotherapy programmes, 18% of those on yoga programmes and 23% of those on instructor-led gym programmes. (Other studies have shown that up to 93% of people with MS report fatigue as a limitation.)
- 5% of the controls in the group who at most use a stick experienced a relapse, while only 1% of those on physiotherapy led programmes experienced a relapse.
- Those in the group physiotherapy programme for people who at most use a stick experienced a 19% reduction in the level of fatigue. Participants noted improvements in energy, ability to recall information and time needed to complete tasks.
- Those in the physiotherapy led programmes for people who at most use a stick experienced a 15% reduction in the psychological impact of MS. Participants noted improvements in their general attitude and happiness.
- 25% of participants in the group physiotherapy programme, who use a rollator or two sticks moved from a high to a low risk of falling. (Other studies have shown that 64% of people with MS report at least two falls per year, affecting confidence in walking and social participation.)
- Those who use a rollator or two sticks and participated in one-to-one physiotherapy programmes experienced a 16% reduction in the level of fatigue.
- Those who use a rollator or two sticks and participated in group physiotherapy experienced a 20% improvement in their balance.
- Those who use a rollator or two sticks in the yoga programmes experienced a 20% increase in their walking ability, improving the distance they were able to walk in six minutes.
- Wheelchair users receiving a standard physiotherapy programme, experienced improvement in the impact of MS. Carer burden was also reduced for this group.

* This is the number of people who received an initial assessment. However, some people may not have participated in the programme due to relapses, ill-health or scheduling issues.

**This statistic comes from research carried out by the Physiotherapist Interested in MS group (PIMS).
USING THE RESEARCH AND GOING FORWARD

One of the main aims of the programme is to provide evidence-based research of the benefits of physiotherapy and exercise interventions for people with MS. The purpose of this is to help MS Ireland provide and advise on improving services. We will use the research to better organise and target our own services. However, our greatest piece of work will be with the HSE to encourage them to adapt the learning's from the programme into the way they deliver physiotherapy and related intervention in the community. For example, we would like to see community physiotherapists running more group physiotherapy programmes. This would significantly increase the number of people benefiting from physiotherapy with no additional staff needed.

The research has shown that participants did not sustain the benefits gained from their programmes; no group maintained benefits after a three month lapse. It is imperative that we find ways to continue the programmes to ensure the long-term benefits of physiotherapy and exercise-based interventions are maintain, thus reducing the demand on services for care and health interventions.

FURTHER INFORMATION AND RESOURCES

• The overall Getting the balance Right report will be published at the end of the year and will be made available widely through our website.
• We have published two guides for people with MS offering an arrange of information around exercise and practical techniques to use at home. MS and Fitness and Everybody Stretch are available to download from our website www.ms-society.ie. These booklets have been adapted from the Canadian MS Society, with kind permission.
• A selection of research papers, many in the area of physical aspects of living with MS e.g. fatigue, mobility, falls and injuries, are available on our website, courtesy of the University of Illinois in Chicago.
• Later in the year, we will be publishing tool-kits outlining how the ‘Getting the Balance Right’ programme can be adapted by physiotherapist. It is hoped this will standardise treatment and ensure maximum benefit for people with MS.
• ‘Getting The Balance Right’ has provided an opportunity for physiotherapists to come together and share experiences and knowledge of their work with people with MS. Physiotherapists Interested In MS (PIMS) are now a formal group who are actively enhancing and developing some of the themes and work from our programme.

THANK YOU

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• Aidan Larkin, National Coordinator of the programme and all our staff teams who organised programmes and participants;
• All those with MS who participated in the various elements of the programme.

For more information on the programme, or any aspect of MS or MS Ireland, log onto www.ms-society.ie or call our helpline on 1850 233 233