

Challenges for Integrated Care Packages in Multiple Sclerosis

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[illegible]

- # While you reflect on your own services

MS Symptoms

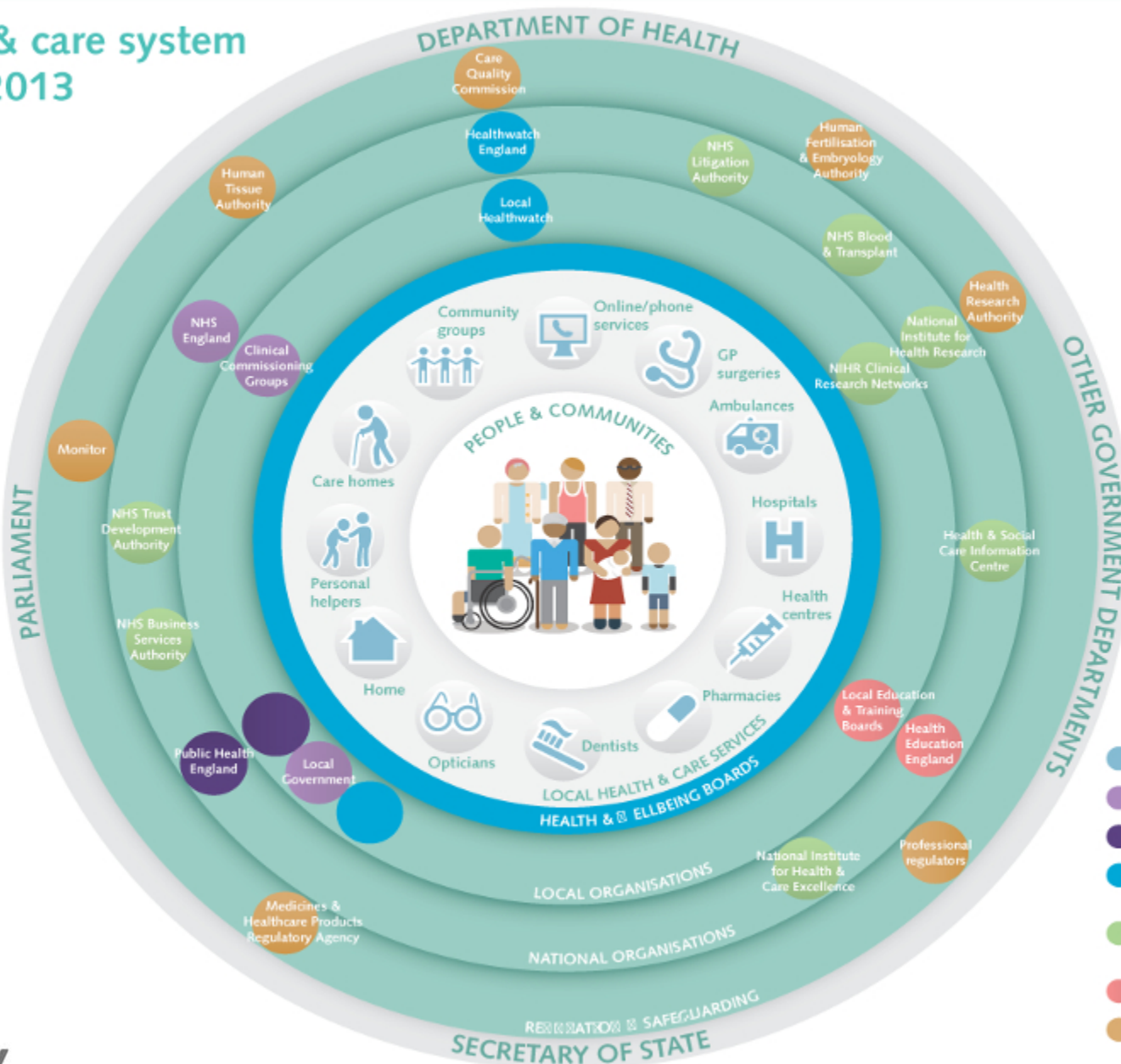
- Fatigue
- Weakness
- Poor co-ordination
- Spasticity
- Sensory disturbance
- Visual disturbance
- Swallowing difficulties
- Bladder & bowel dysfunction
- Sexual dysfunction
- Communication difficulties
- Pain
- Vertigo
- Cognitive difficulties
- Depression & anxiety

Problems usually due to comb'n of factors:

- physical
- psychological
- environmental
- socio-cultural
- economic factors

...comprehensive assessment and mdt
management required

The health & care system from April 2013

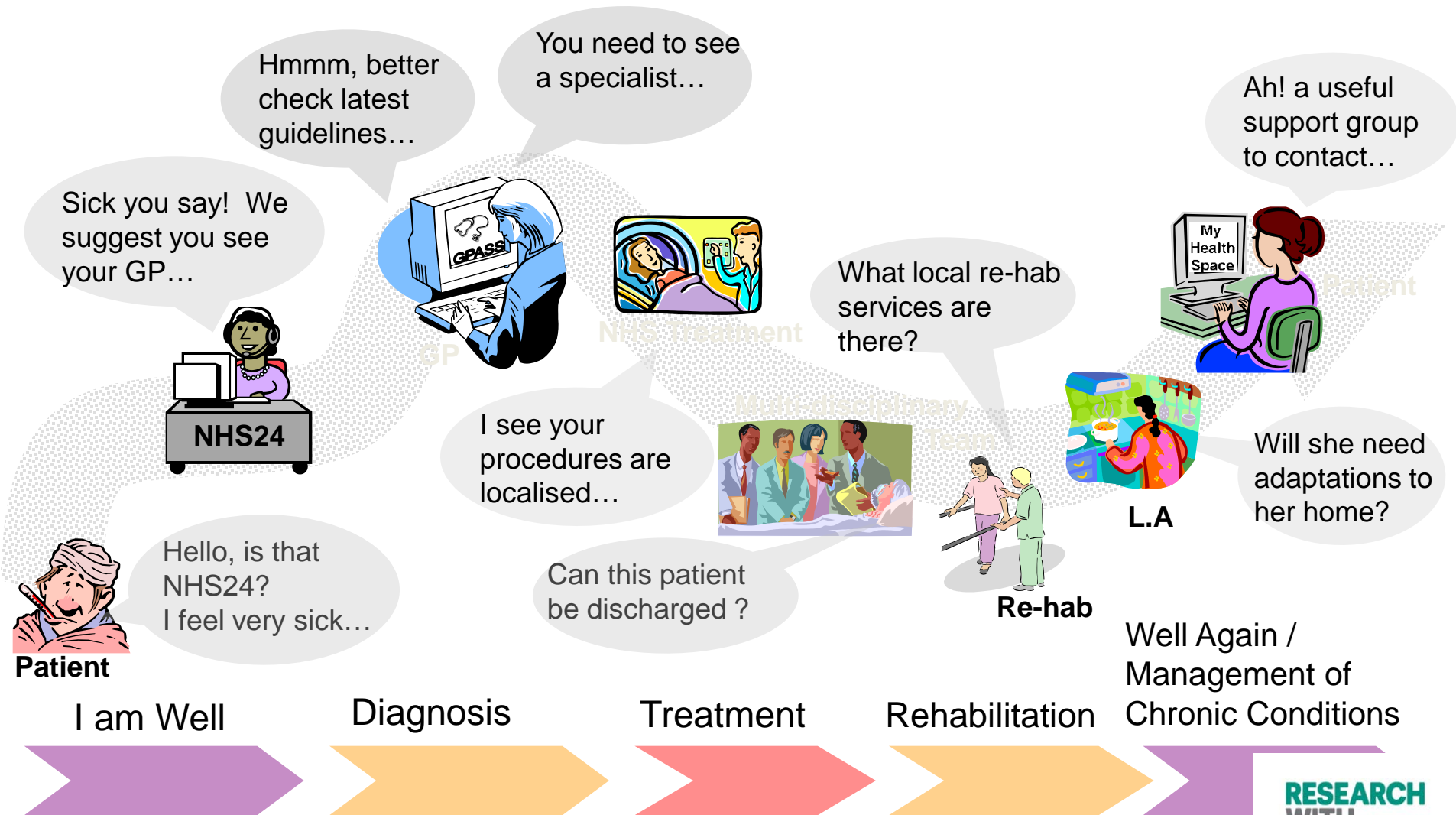




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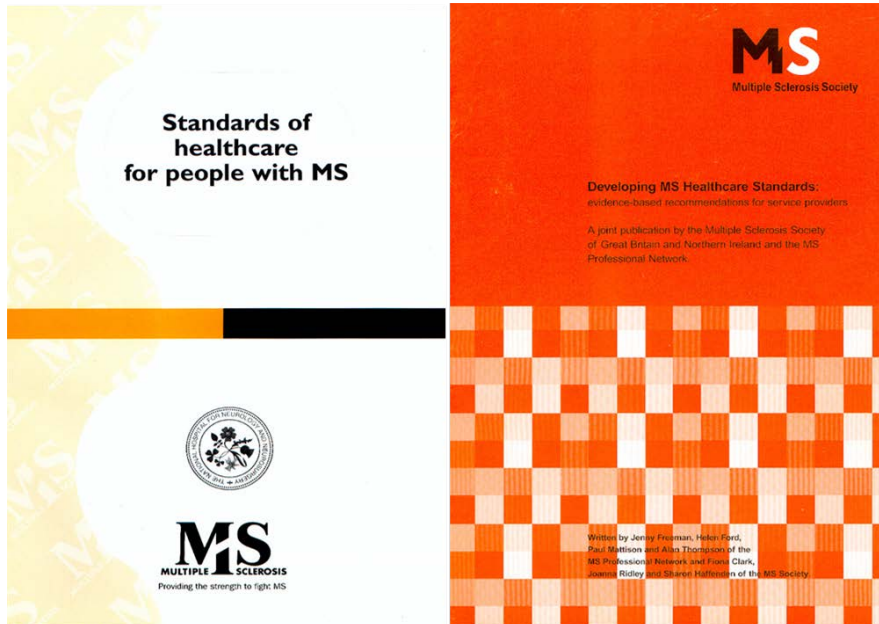
Patient Journey





Variable, unpredictable, multi-factorial,
generally progressive.... constantly changing
need over the course of a lifetime

What people with MS want from services



- acknowledgement that they know what they're talking about
 - expertise in living and dealing with the disease
 - may offer new insights in care
- “partners in care”
- ongoing relationships rather than fragmented series of “quick-fixes”
- supportive care centered on their individual needs

Stages

Needs

Initial
(diagnostic phase)

certainty of diagnosis, clarity of communication, support, information

Early
(minimal disability)

advice re: how to stay well, family, employment, housing, economic planning,

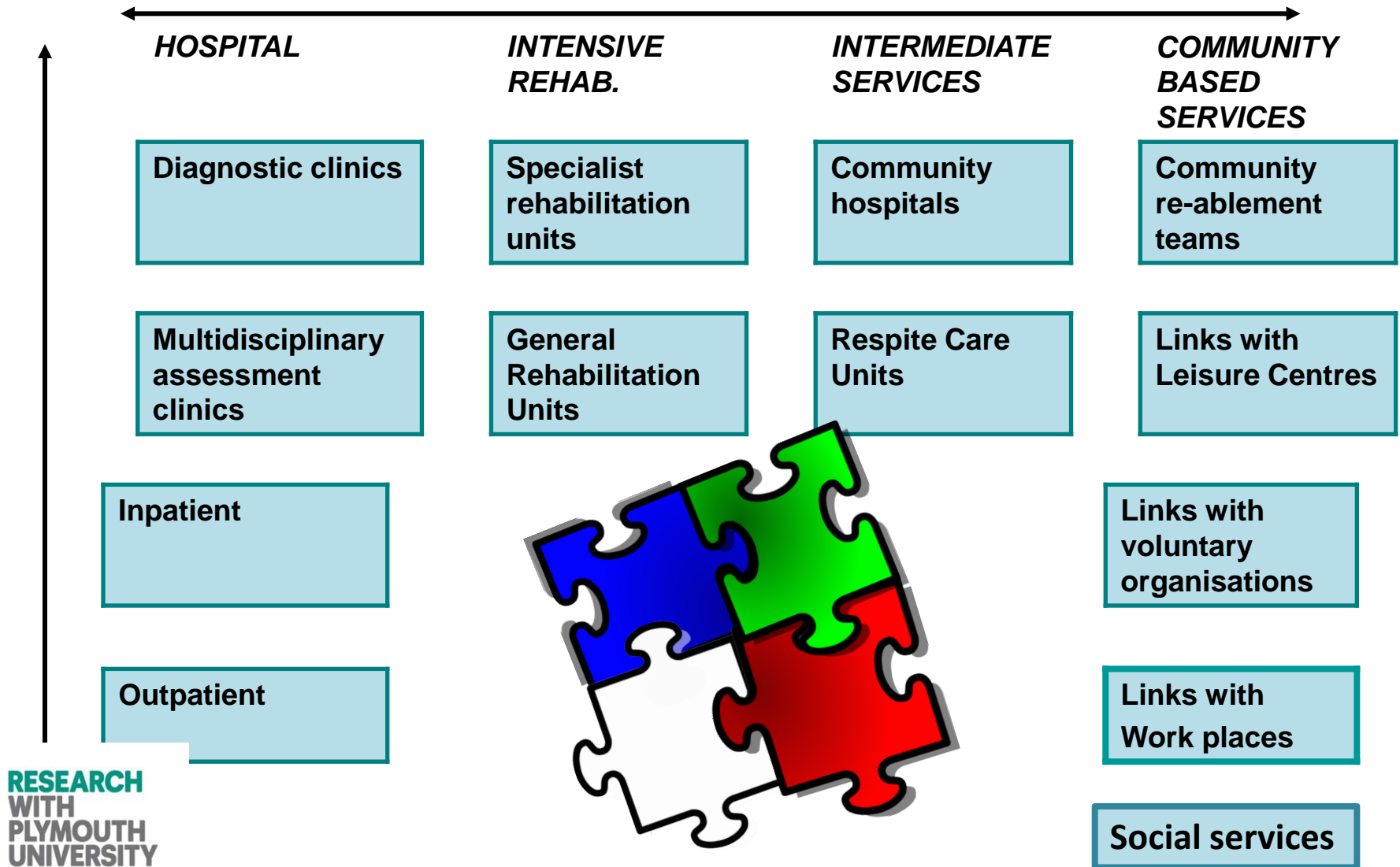
Late
(moderate disability)

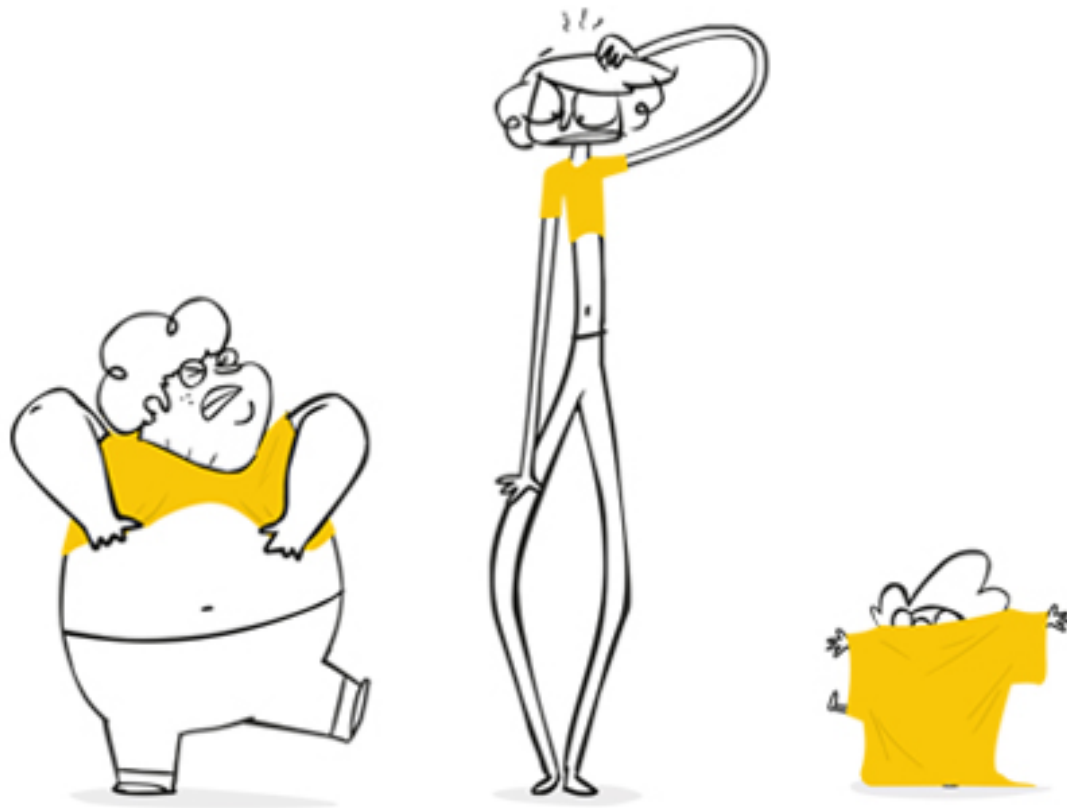
symptomatic management, rehabilitation

Advanced
(severe disability)

support for carer, equipment, home adaptations, respite

REHABILITATION SERVICES FOR PEOPLE WITH MS: a coherent “whole systems” approach to care delivery





**ONE
SIZE
FITS
ALL**

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Measuring Success

An audit tool for health care professionals

New edition 2007

...improving services for people with MS

INTRODUCTION

Edition two of this audit document is for use auditing the six key priorities in the *National Institute for Health and Clinical Excellence (NICE) Guideline No 8, Management of Multiple Sclerosis in primary and secondary care*, published in 2003 and is cross referenced to *The National Service Framework (NSF) for Long-term Conditions*, published in 2005.* It will assist you in determining the services achievement in complying with best practice against the NICE and NSF guidelines and identifying areas requiring further development.

HOW TO USE THIS AUDIT TOOL

Following on from the evaluation of edition one, the second edition tool is laid out in sections to allow commissioning, primary, secondary and neuro-rehabilitation services to audit themselves. This is in response to the situations where not all items were pertinent to all service areas. The sectional layout allows services to concentrate on those areas where they can effect service improvement. This has necessitated an element of duplication as the key priorities apply across the divisions of care. All services should complete the general principles section.

Each of the key priorities is listed, accompanied by the data items required by NICE as evidence of performance, along with examples of how the priorities can be implemented locally.

Each of the general principles within the NICE Guideline is listed and you are asked to consider whether your service is able to meet them **fully, partially or not at all**. These are cross referenced as mapping links to the NSF for long-term conditions giving the NSF document page number, the Quality Requirement and the evidenced based markers in brackets. You should consider being able to supply the evidence to back up your assertions.

Once you have undertaken the audit process, you should then consider each area in more detail, using the Audit Action Plan (Appendix 1) and develop your ideas for service development and improvement.

*This document draws on the *National Institute of Health and Clinical Excellence Guideline No 8 Management of Multiple Sclerosis in primary and secondary care* 2003 and the Department of Health *National Service Framework for Long-term Conditions*, 2005, both of which are subject to copyright. Any permission requests should be directed towards the individual organisations.

GEMSS – Generating Evidence in Multiple Sclerosis Services



Where am I? [Home](#) [Health Professionals](#) [GEMSS](#)

GEMSS

Generating Evidence in Multiple Sclerosis Services

What is GEMSS?

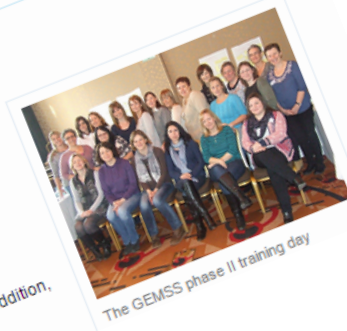
Generating Evidence in Multiple Sclerosis Services (GEMSS) is an MS Trust project launched in 2012 to help MS specialist nurses and MS specialist teams evaluate their services and demonstrate what works best to meet the needs of people with MS and their families.

[Download the latest briefing on the GEMSS programme \(PDF\)](#)

What are we hoping to achieve?

GEMSS aims to build the skills and capabilities of nurses involved in the project and at the same time help to develop a culture of continuous improvement in the services that are being evaluated. In addition, the project aims to leave a lasting legacy for MS services by developing a set of common quality standards and tools by which they can be measured.

Results of evaluation will be presented at MS Trust Conference , Nov 2015



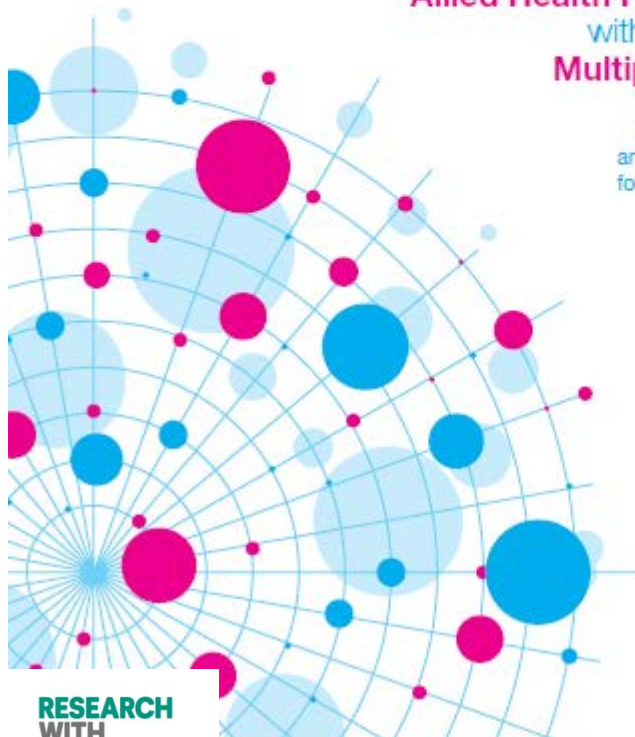


Defining the value of Allied Health Professionals with expertise in Multiple Sclerosis

Supporting Evidence
and Recommendations
for Commissioners and
Practitioners

Authors
Katy Dix
Howard Green

November 2013

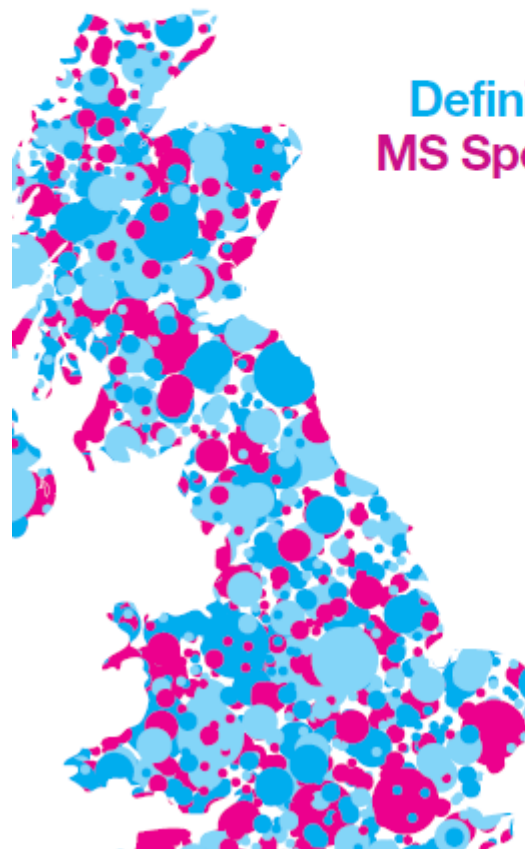


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Defining the value of MS Specialist Nurses

Authors
Geraldine Mynors
Sarah Perman
Martin Morse

March 2012



IMPROVING ADULT REHABILITATION SERVICES IN ENGLAND

Sharing best practice in
acute and community care



30 Case studies

CASE STUDY 10

Staffordshire and Stoke on Trent Partnership NHS Trust
Audit Ability: Specialist nursing and therapy services for people with progressive neurological conditions

Context

Thirty years ago a consultant physician at Queen's Hospital, Burton-on-Trent, had a vision to offer a case management service for local people aged between 16 and 65 with long-term complex physical conditions, to ensure their needs were met in a timely way and that their care was not 'forgotten' in the system.

A team of healthcare professionals were brought together and met monthly for lunchtime review meetings, and as a result of this approach one full-time (funded) position was split between an occupational therapist and physiotherapist to provide active rehabilitation.

Action

In 2005 a business case for funding was approved which transformed the service into a specialist nursing and therapy team for people with progressive neurological conditions. The provision of care was moved from the local acute Trust to the community and the current team operates across East Staffordshire (population of approximately 135,000) and parts of South Derbyshire.

Today the Staffordshire and Stoke on Trent Partnership NHS Trust 'Adult Ability' team consists of ten staff (including multiple sclerosis and Parkinson's disease clinical nurse specialists, physiotherapists and occupational therapists, a support worker and team administrator) working with a case load of around 600 patients with a range of different conditions, such as Parkinson's disease, multiple sclerosis, Huntington's disease and Motor-Neurone disease.

Self-management is intrinsic to the philosophy of care provided by the team and their key principles are:

- Person centred assessment and treatment (physical, cognitive, psychological, emotional)
- A restorative approach – rehabilitation targeting neurological impairment with a goal of improving deficit or maintaining existing function

- Compensation strategies – changing approach, techniques or behaviours to accommodate deficits and manage difficulties
- Environmental modifications
- Encouraging participation
- Life style management
- Liaison with other services – statutory and voluntary

The service operates Monday to Friday 8.30am to 4.30pm. Referrals are normally received through GPs (19 surgeries in the locality) or hospital-based neurologists, and are triaged on a needs basis - with the most urgent cases seen within five to seven working days. Care is provided from diagnosis through to end of life (for adults aged 18 years and over). Once an episode of intervention is complete the service user can re-activate further interventions or advice as required via a single point of access.

Patients are seen at home, in clinic-based settings, at work, or wherever difficulties may occur. Members of staff also run a number of group education and physical fitness sessions in different venues around the locality. Outcomes are measured and reported back to the referring GP (where relevant). Once a year every practice in East Staffordshire is offered a case review of their patients with members of the team visiting surgeries to discuss individual cases. This helps maintain a positive relationship with local referrers and enables them to track the progress of their patients.

Impact

- Annual service user audit from last year revealed 93% of respondents rated the quality of care as good or very good
- The West Midlands Quality Review for Long-Term Conditions from 2013 stated:
 - The Adult Ability Team provided good, integrated care for people with progressive neurological conditions
 - There was a strong focus on keeping people out of hospital and good links with the hospital-based service for discussion of patients' needs

Common Elements of Successful Rehabilitation Services

- 1. Integrated service models with health and social care**
 - a. Commissioning support for an integrated model**
 - b. Integrated IT systems**
- 2. Single point of assessment / co-ordinated referral**
- 3. Early intervention**
- 4. Self-management**
- 5. Self-referral**
- 6. Flexibility of workforce**

Common Elements of Successful Rehabilitation Services

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3. Early intervention
4. Self-management
5. Self-referral
6. Flexibility of workforce

- “It’s like a ping pong ball, you just go backwards and forwards.... you’re left in suspense all the time”
(Person with MS)
- “I think our coordination could be much better. I don’t meet regularly with the therapists involved in seeing my patients so we communicate at an arm’s length, really by letter. ... the communication is rather distant and not particularly swift.”
(Neurologist)



e.g. Mobility Clinic

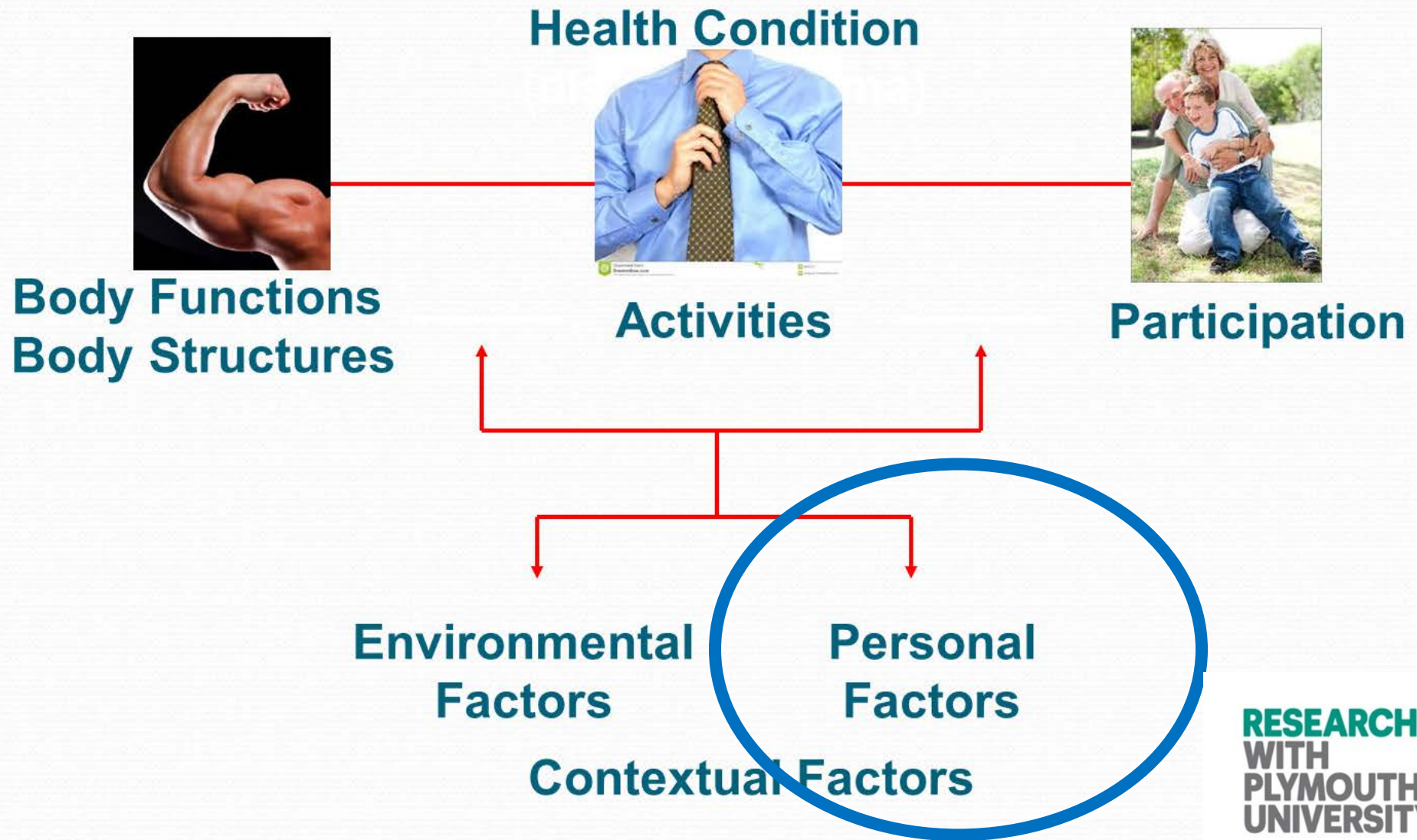


e.g. Co-ordinated MDT Clinics

| | MON | TUE | WED | THUR | FRI |
|----|-----------------------------|----------------|----------------|---------------|------------|
| AM | Therapy Clinic (OT / PT) | Fatigue Clinic | | Physio Clinic | MDT Clinic |
| PM | | FES Clinic | Relapse Clinic | | |

Linked to & audited against NSF & NICE Guidelines

The Integrative Model of Functioning and Disability



Common Elements of Successful Rehabilitation Services

1. Integrated service models with health and social care
 - a. Commissioning support for an integrated model
 - b. Integrated IT systems
2. Single point of assessment or referral
3. Early intervention
- 4. Self-management**
- 5. Self-referral**
6. Flexibility of workforce



Self referral

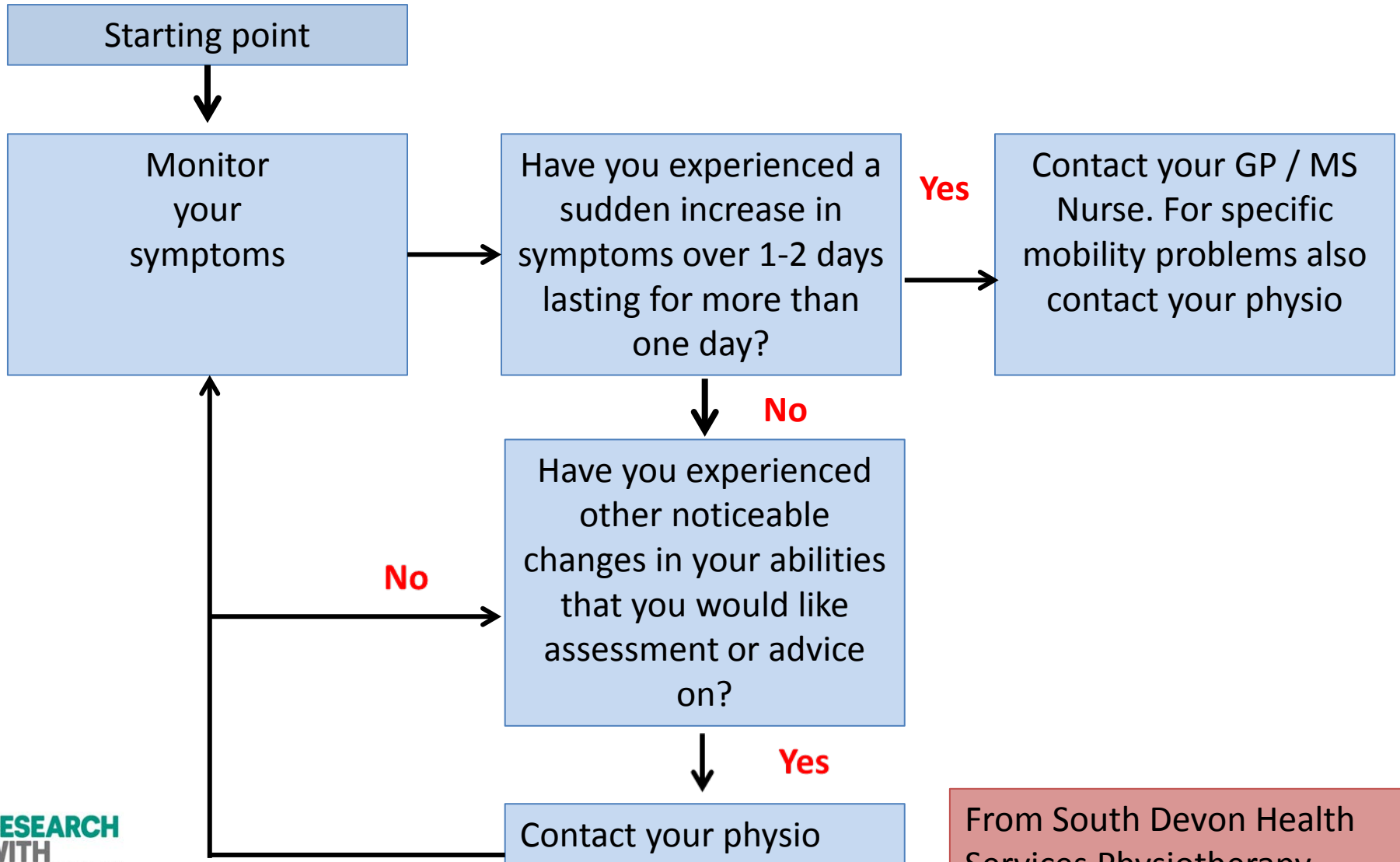


- **Choice:** to have the capacity and power to act alone/ decide when to act
- **Direct access** (no need for intermediary such as GP)
- An **immediate response** (awareness of what will happen next).

Challenges with Self referral

- Cognitive impairment
- Rapidly changing / hard to manage symptoms
- Lack of confidence
- Unsure when to self refer to health professionals for further help
 - “Don’t wish to worry the Dr syndrome”
 - Lack of knowledge re what is available

Self referral: Flowchart



Adopting a “rehabilitation approach”.... from the point of diagnosis

Rehabilitation is....

“an **active process of change** wherein a person who has become disabled **acquires and uses the knowledge & skills** necessary for optimal physical, psychological & social function”

(RCP, 1991)

“a **problem-solving process** aimed at improving a persons quality of life, within the limits imposed by the available resources and the underlying disease” (WHO 1980)

“..equipping a person with **effective coping skills** so that they can manage deficits and **apply solutions to challenges**”



(Supported) Self management

1. To promote a sense of self-management and control over symptoms
2. To facilitate adjustments thorough peer support and the sharing of experiences in a group.
3. To provide information on strategies and resources to maximize knowledge and independence.

CHANGE IN BEHAVIOUR

Conference
'Living Well with MS'
26th September 2015



[Home](#) > [Community](#) > MS and Me

MS & Me: A Community Blog for People Living with MS



Fertility and Pregnancy Part 2

Last week Emma wrote about MS and the fertility and pregnancy journey. This week she delves deeper into the joys and challenges of having a new-born in her life. One of my exes told me when we broke up that she pitied me- no-one would want...

[Read more](#)

Author: Emma Bogan - 24 Sep 2015



Welcome to our MS community

Lowered physical activity level

Physical activity and multiple sclerosis: a meta-analysis

Robert W Motl, Edward McAuley and Erin M Snook*

Department of Kinesiology, University of Illinois at Urbana-Champaign, Urbana, IL, USA

Using meta-analytic procedures, this study involved a quantitative synthesis of the difference in physical activity among individuals with multiple sclerosis (MS) compared with nondiseased and diseased populations and then examined factors (i.e., moderators) that explain variation in the overall difference in physical activity. We searched MEDLINE, PsycINFO and Current Contents Plus using the key words physical activity, exercise and physical fitness in conjunction with multiple sclerosis; conducted a manual search of bibliographies of the retrieved papers; and contacted study authors about additional studies. Overall, 53 effects were retrieved from 13 studies with 2360 MS participants and yielded a weighted mean effect size (ES) of -0.60 (95% CI = -0.44 , -0.77). The weighted mean ES was heterogenous, $Q = 1164.11$, $df = 52$, $P < 0.0001$. There were larger effects with objective versus self-report measures of physical activity, nondiseased versus diseased populations and primary progressive versus relapsing-remitting MS. The cumulative evidence suggests that individuals with MS are less physically active than nondiseased, but not diseased, populations.

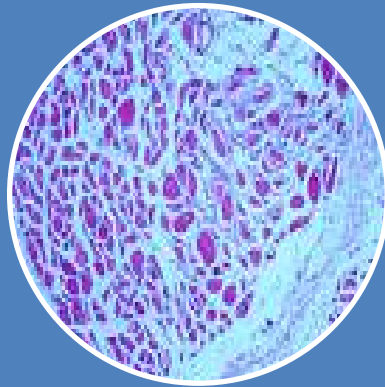
Multiple Sclerosis (2005) 11, 459–463

Mult. Scler 2005; 11:4:459-63

Exercise Research: Bench to Bedside



Neuroplasticity
Neural health
Immunology



Muscle
and
neural physiology



Factors impacting
on exercise
capability



Evaluation of
effectiveness

Collaboration between basic scientists, clinical trialists and clinicians

Forms of exercise used by pwMS

Strengthening

Aerobic exercise

Combined aerobic /resistance

Treadmill training (regular, robot-asst'd

Cycling ergometry

Pilates

Yoga

Tai chi

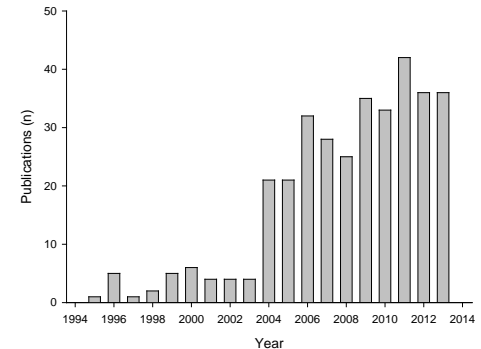
Group classes general ex.

Swimming

Hydrotherapy

Wii

Explored in trials of MS



Safety of Exercise

26 studies, n = 1295

Relapse Rate Ex = 6.3%

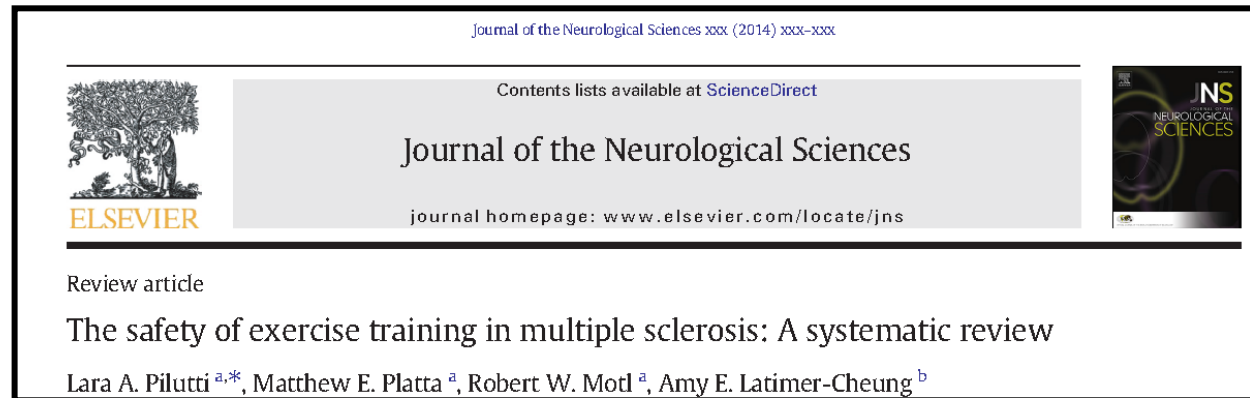
Relapse Rate Control = 4.6%

RR relapse Ex 0.73

RR relapse Control = 1.67

AE's Ex = 2% (no higher than healthy populations)

AE's Control 1.2%



Short Report

Multiple sclerosis relapses are not associated with exercise

A Tallner¹, A Waschbisch², I Wenny², S Schwab², C Hentschke¹, K Pfeifer¹ and M Mäurer^{2,3}

Abstract

Since multiple sclerosis (MS) often affects physically active young individuals, it is important to know if exercise can result in increased disease activity. Therefore we used a self-report questionnaire to examine the relationship of different levels of sports activity and relapses in 632 patients with MS. In order to analyse whether subjective recall might have biased the results, we performed, in a subgroup of our sample, an objective assessment of clinical data and physical fitness parameters. We were unable to find any association between sports activity and clinical relapses in either of the two analyses. The group with highest activity even shows the lowermost mean values, standard deviations and range concerning the number of relapses. Our data suggest that physical activity has no significant influence on clinical disease activity.

Multiple Sclerosis
JOURNAL

Multiple Sclerosis Journal
0(00) 1-4

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DOI: 10.1177/1352458511415143

msj.sagepub.com



SAGE

N=632

Self-report
questionnaire

No sig differences
b/w exercisers /
non exercisers in
self report relapses
previous 2 yr's

Effects of Exercise therapy

| | MS patients vs. healthy controls |  |  |
|----------------------------|----------------------------------|---|---|
| Muscle strength | ↓ | ↑↑ | ↑↑ |
| Muscle mass | ↓ | ↑ | ↑ |
| Muscle activation | ↓ | ↑ | ↑ |
| Aerobic capacity (VO2-max) | ↓ | ↑↑ | |
| CVD risk | ↑ | ↓ | ↓ |
| Depression | ↑ | ↓ | ↓ |
| Fatigue | ↑ | ↓ | ↓ |
| Daily activity level | ↓ | ↑ | ↑ |
| Functional capacity | ↓ | ↑ | ↑ |
| Balance | ↓ | ↑ | ↑ |
| QoL | ↓ | ↑ | ↑ |

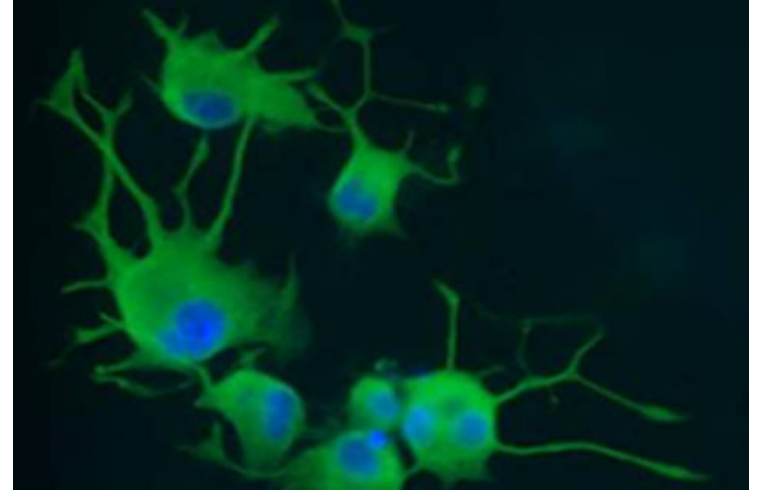
Red arrow = Impaired in MS patients

Green arrow = Improved after exercise in MS patients

Potential Impact of Physical Activity on Brain Health and the Immune System

Mediates processes:

- Neuroprotective,
- Neuroregenerative,
- Adaptive (Neuroplasticity)



enhancement of neurotrophic factors

enhance stress resistance

influences balance of pro/anti-inflammatory response

(Gold et al 2003; Heesen et al 2003; White et al 2006; White and Castellano 2008; Golzari et al. 2010)

REVIEW ARTICLE (META-ANALYSIS)

Effects of Exercise Training on Fitness, Mobility, Fatigue, and Health-Related Quality of Life Among Adults With Multiple Sclerosis: A Systematic Review to Inform Guideline Development



Amy E. Latimer-Cheung, PhD,^a Lara A. Pilutti, PhD,^{b,c} Audrey L. Hicks, PhD,^b
Kathleen A. Martin Ginis, PhD,^b Alyssa M. Fenuta, HBS, K. Ann MacKibbin, PhD,^b
Robert W. Motl, PhD^c

From the ^aSchool of Kinesiology and Health Studies, Queen's University, Kingston, Ontario; ^bDepartment of Kinesiology, McMaster University;

Canadian Physical Activity Guidelines and Canadian Sedentary Behaviour Guidelines

www.csep.ca/guidelines

Use the links below to download or order the [Canadian Physical Activity Guidelines](#) and [Canadian Sedentary Behaviour Guidelines](#) info sheets and related resources. For more information and background on the Canadian Physical Activity Guidelines and Canadian Sedentary Behaviour Guidelines, please visit the [Background Information page](#).

Link to page: [Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis](#)

Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis

| Guidelines Info Sheet | UPDATED! September 2013 Guidelines for MS Toolkit | UPDATED! September 2013 Toolkit Insert |
|-----------------------|---|--|
| | | |

Resistance Exercise: 2-x week at moderate intensity (60-80% 1RM, 10 – 15 repetitions, 1-3 sets), minimum 8 weeks

Aerobic Exercise: 2-3/week at moderate intensity (60-80% max HR), 30 minutes, minimum 4 weeks

Increasing physical activity: Integrating care by crossing the boundaries

In the clinic:
one of the first questions to ask is....

What are you currently doing to manage your health?

What exercise do you currently undertake?

Is there anything that is putting you off exercising?

Lets see how I can help as exercise has proven to be beneficial.

Gait and balance impairment in early multiple sclerosis in the absence of clinical disability

CL Martin^{1,2}, BA Phillips^{1,2}, TJ Kilpatrick^{3,4}, H Butzkueven^{3,4}, N Tubridy^{3,6}, E McDonald⁵ and MP Galea^{1,2}

This study evaluated the gait and balance performance of two clinically distinct groups of recently diagnosed and minimally impaired multiple sclerosis (MS) patients (Expanded Disability Status Scale range 0–2.5), compared to control subjects. Ten MS patients with mild pyramidal signs (Pyramidal Functional Systems 1.0), 10 MS patients with no pyramidal signs (Pyramidal Functional Systems 0) and 20 age- and gender-matched control subjects were assessed using laboratory-based gait analysis and clinical balance measures. Both MS groups demonstrated reduced speed and stride length ($P < 0.001$), and prolonged double limb support ($P < 0.02$), compared to the control group, along with alterations in the timing of ankle muscle activity, and the pattern of ankle motion during walking.



Contents lists available at SciVerse ScienceDirect

Gait & Posture

journal homepage: www.elsevier.com/locate/gaitpost



Body-worn motion sensors detect balance and gait deficits in people with multiple sclerosis who have normal walking speed

R.I. Spain^{a,*}, R.J. St. George^b, A. Salarian^c, M. Mancini^b, J.M. Wagner^d, F.B. Horak^b, D. Bourdette^a

^aNeurology Service and MS Center of Excellence-West, Portland VA Medical Center and Department of Neurology, Oregon Health & Science University, Portland, OR, USA

^bDepartment of Neurology, Oregon Health & Science University, Portland, OR, USA

^cBalance Disorders Lab, Oregon Health & Science University, Beaverton, OR, USA

^dDepartment of Physical Therapy and Athletic Training, Saint Louis University, St. Louis, MO, USA

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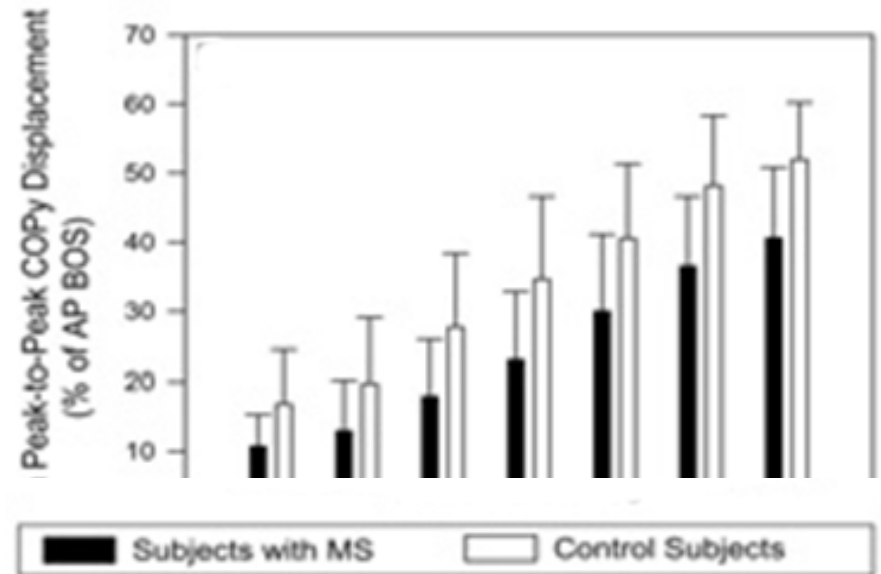
ABSTRACT

While balance and gait limitations are hallmarks of multiple sclerosis (MS), standard stopwatch-timed measures practical for use in the clinic are insensitive in minimally affected patients. This prevents early detection and intervention for mobility problems. The study sought to determine if body-worn sensors could detect differences in balance and gait between people with MS with normal walking speeds and

- Reduced speed
- Shorter strides
- Prolonged double limb support phase
- Altered muscle activity and kinematics
- Skeletal changes

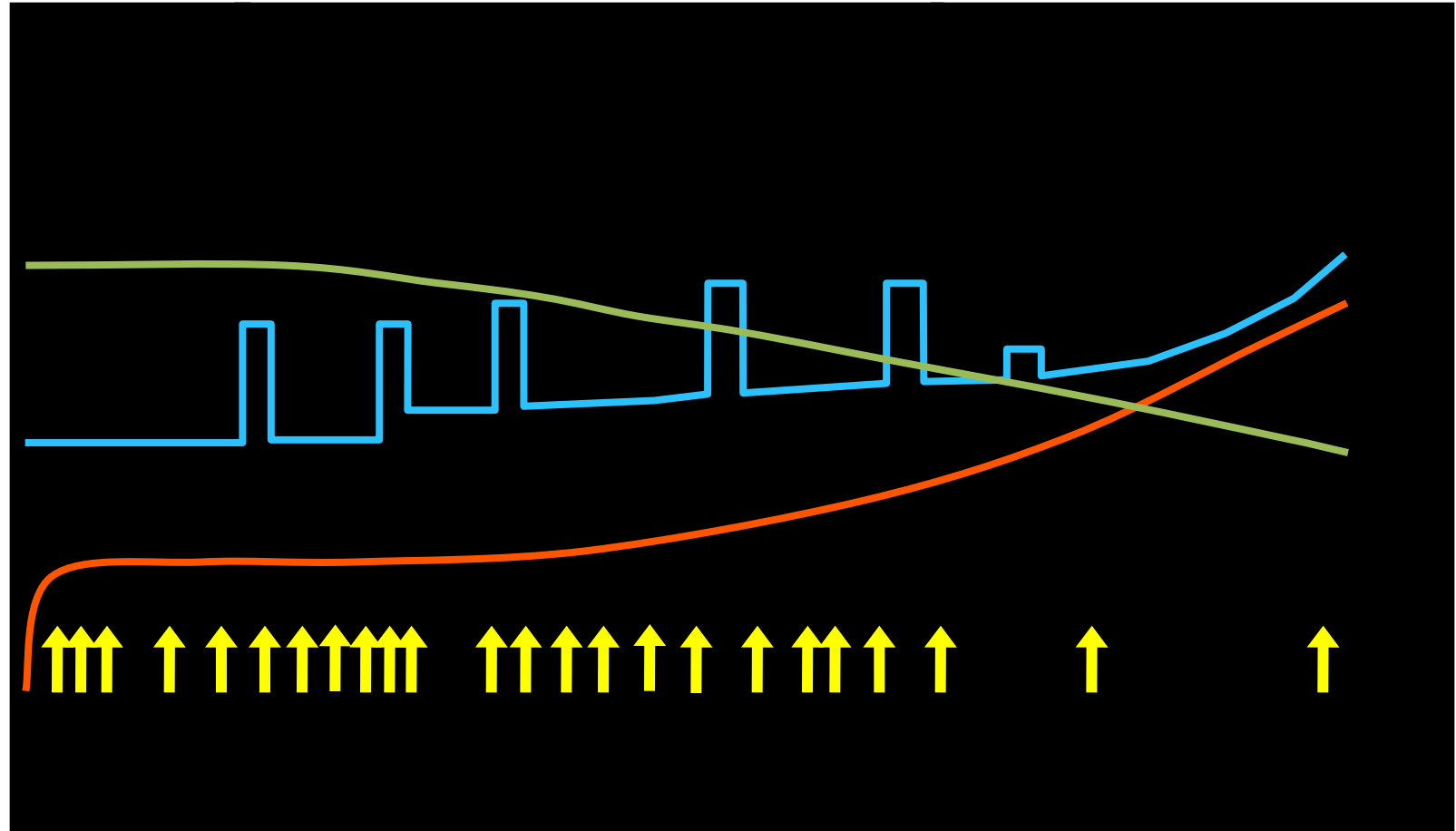
(Gehlsen et al 1986, Benedetti 1999, Morris 2002; Savci 2005, Martin 2006)

Balance impairment in those with no / minimal functional disability



(Kurst 2005, Martin 2006)

Natural History of MS: inflammation & axonal degeneration



MRI activity



Relapses and impairment



Measures of brain volume



MRI Total T2 lesion area



A gym based group intervention for people with MS and high level balance dysfunction

Tania Burge, MS Specialist Physiotherapist

Angela Davies Smith, MS Research Physiotherapist

David Cottrell, Consultant Neurologist



Circuits and cardio training



Multi tasking element



Hand ball



Cricket





- Engaging sustaining physical activity when living with a chronic disability, is complex
- Existing standardised evidence based exercise programmes don't take this into account
- Interviews highlighted that individuals :
 - Want control and choice (ownership of activity chosen)
 - Exercise to be individually tailored - one size does not fit all
 - Highly value ongoing physiotherapy expertise and support

“tell us what you want, what you really really want ”



(Hale et al 2012)

Community

Blue Prescription Scheme

One-to-one

Blue Prescription:

“Choice, ownership, control and support”

Week 1: First visit by physiotherapist to participants home

- Helps the person to “prescribe” their own physical activity using Motivational Interviewing
- Problem solving re access and participation in chosen activities

Week 2–3: Second visit by physiotherapist to participants home

- Goal setting, Problem solving

Week 4: Follow-up visit

- Progress check, Review of goals, Problem solving

Week 12: Follow-up and final visit

- Use of volitional tool to identify barriers/ enablers to long term participation in chosen activity

Throughout intervention: Contact through medium of choice e.g. text messaging, e-mail and telephone.

(Smith et al 2013)

Other successful models

Sports projects for people with MS

Paul Van Asch, Belgium

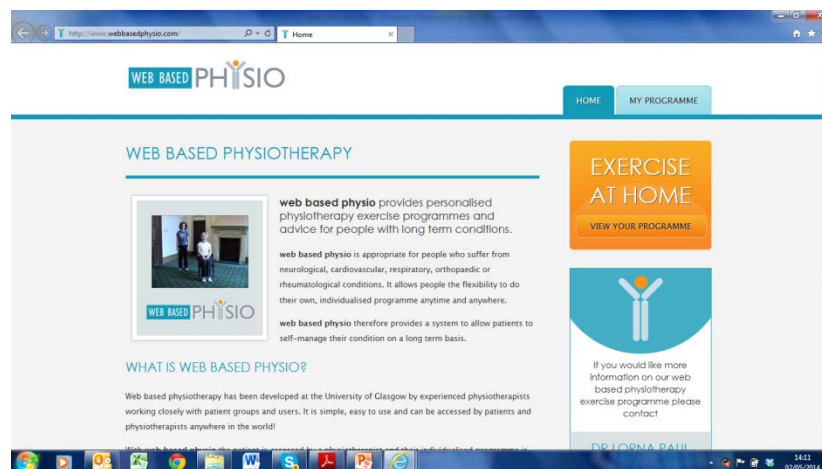


**Move
To Sport**

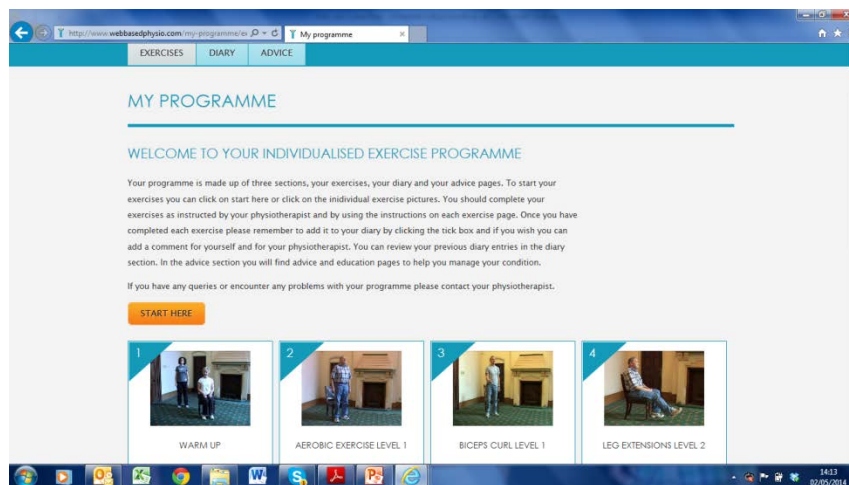
Web-based Physiotherapy

Telerehabilitation

- Using technology to deliver rehabilitation services over a distance
- Can provide an alternative to face to face therapy
- Can support self management through personalised targeted programmes



Targeted programme developed following a face to face physiotherapy assessment:



Wii / exergaming

Theoretical basis:

- Frequent, repetitive, varied movement essential for plasticity
- Ongoing feedback and progression of activities to ensure they are challenging

Typically:-

- 3-5 sessions/week
- 30 minute sessions
- Supervised / Not supervised
- Balance activities progressed
- Patient choice of games incorporated
- Telephone support / monitoring provided in some studies (eg Prosperini 2013)



Results of Wii/ exergaming studies suggest

- Results in terms of improved balance / mobility compare to conventional balance training (but are not better)
- Adherence is very good in short term; although wanes over time
- Safety good (no incidents while training in any study) – adverse events related to knee pain / hip pain similar to healthy literature (Prosperini 2013; Plow 2011)
- May reduce falls

Internet based educational and exercise programmes

- Internet based physical activity intervention (Dlugonski et al. 2011, Motl and Dlugonski 2011, Dlugonski et al. 2012)
 - Modules on Getting Started; Planning for Success; Beating the Odds; and Sticking with It
- Focus on increasing exercise self-efficacy, which is a key correlate of physical activity
- Aim to change long term behaviour

Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle (FACETS).

Downloaded from jnnp.bmj.com on March 4, 2014 - Published by group.bmj.com

Multiple sclerosis



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RESEARCH PAPER

A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis

Sarah Thomas,¹ Peter W Thomas,¹ Paula Kersten,² Rosemary Jones,³ Colin Green,⁴ Alison Nock,⁵ Vicky Slingsby,⁵ Angela Davies Smith,³ Roger Baker,¹ Kathleen T Galvin,⁶ Charles Hillier⁵

ABSTRACT

Background Fatigue is a common and troubling symptom for people with multiple sclerosis (MS).

Aim To evaluate the effectiveness and cost-effectiveness of a six-session group-based programme for managing

INTRODUCTION

Fatigue is one of the most commonly reported and disabling symptoms of multiple sclerosis (MS);¹ 65% of people with MS consider it one of their three most troubling symptoms.² MS-fatigue differs

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/jnnp.2013.2816>).

rch Unit School

Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle (FACETS).

- 6 week 90minute group-based manualised intervention
- Led by MS specialist health professionals , supported by a clinical psychologist
- Conceptual framework integrating cognitive behavioural, social-cognitive, energy effectiveness, self-mg't & self-efficacy theories
- Aims to help people normalise their fatigue experiences, learn helpful ways of thinking about fatigue & use energy more effectively
- Highly structured - facilitator-delivered presentations, flipchart discussions, group activities, homework.
- Delivered in hotel meeting-room facilities

FACETS Results

- Sig ↓ fatigue severity and ↑ fatigue self-efficacy.
- Improvements in fatigue severity not apparent until follow-up (2-4 months post intervention)
- Changes in attitudes / lifestyle central to the programme are likely to take time to incorporate into daily routines.
- The ActivPAL data - ↓ fatigue not due to ↓ activity levels
- No changes in disease specific QOL (this may take longer?)
- Evaluation questionnaires - high overall satisfaction, high attendance rates

Social isolation

- PwMS may experience exclusion and isolation.
- Difficult to access health services
- Difficult to engage in community based activities
- Difficult for third sector organisations to engage
- A generally “neglected” group

In depth Interviews n = 16

- Reported feeling they did not have the power, control, or ability to be able to do what they wanted to
“you’re a member of a club you don’t want to be a member of”.
- Other people made decisions as to whether and when they were on their own; there was little they could do about this.
- Poor mobility , fatigue and continence issues further exacerbated isolation

(Robens et al 2015)

Loss of identity:

“It’s finding that you are probably of your own volition, um, a non-person to the rest of the world. Because you are committed to your own relatively small environment, so most of the world doesn’t, because you’re not out there and of it, you’re... the isolation is actually more of an enclosure. You’re not part of that great outside world.” P1

(Robens et al 2015)

Loss of identity:

“I’ve spent an awful lot of time just sat doing not much... which after sixty plus years of messing about, um, kind of alienates me....I suppose it’s because I’ve always been able to do all of that, whether it’s DIY or works, or making things, whoever, the not being able to do it is of itself isolating.” (P1)

(Robens et al 2015)

What is needed:

Crossing service boundaries

Support to carers:

- Family carers are the key to people accessing the world.
- Most had little or no support.
- Carers wellbeing directly impacts on the wellbeing of those they care for.

(Robens et al 2015)

Personalised approaches:

Think outside of traditional support mechanisms.

Examples include:

- the use of Personal Health Budgets
- easing mobility and continence difficulties
- access to Depression and Anxiety Services
- Linking with third sector organisations “befriending scheme”

To be effective and sustainable, choice, control and identity must be central to services provided.

(Robens et al 2015)

Summary

Problems in MS are often:

- multi-factorial,
- complex,
- evolve throughout the disease course

Therefore:

- Integrated health, social care and third sector input is essentialbut challenging
- No one size fits all
- Timely intervention may be enhanced by self referral
- Targeted assessment / intervention
- “management” rather than “quick-fix” interventions
- Focus on supported self management / long term behavioral change
- And personalised care which consider each person as the individual that they are

Thank you for listening
Any questions?

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