Challenges for Integrated Care Packages in Multiple Sclerosis

Jenny Freeman
Plymouth University
Faculty of Health and Human Sciences
Outline of talk

• The issues facing people with MS
• (Some of) the challenges that result
• Tackling the challenges .......
• From an organisational perspective
• With examples of evidence based interventions

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
Patient Journey

I am Well

Diagnosis

Treatment

Rehabilitation

Hmmm, better check latest guidelines…

You need to see a specialist…

What local re-hab services are there?

Ah! a useful support group to contact…

Sick you say! We suggest you see your GP…

I see your procedures are localised…

Can this patient be discharged?

Hello, is that NHS24? I feel very sick…

Well Again / Management of Chronic Conditions

Will she need adaptations to her home?

NHS24

GP

NHS Treatment

Multi-disciplinary Team

L.A

Patient

Patient

Patient

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

(Hatch 1997, Robinson 1996)
<table>
<thead>
<tr>
<th>Stages</th>
<th>Needs</th>
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<tr>
<td><strong>Initial</strong> (diagnostic phase)</td>
<td>certainty of diagnosis, clarity of communication, support, information</td>
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<tr>
<td><strong>Early</strong> (minimal disability)</td>
<td>advice re: how to stay well, family, employment, housing, economic planning,</td>
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<td><strong>Late</strong> (moderate disability)</td>
<td>symptomatic management, rehabilitation</td>
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<td><strong>Advanced</strong> (severe disability)</td>
<td>support for carer, equipment, home adaptations, respite</td>
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*(MS Society Great Britain 2002)*
REHABILITATION SERVICES FOR PEOPLE WITH MS: a coherent “whole systems” approach to care delivery

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<tr>
<th>HOSPITAL</th>
<th>INTENSIVE REHAB.</th>
<th>INTERMEDIATE SERVICES</th>
<th>COMMUNITY BASED SERVICES</th>
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<td>Specialist rehab.</td>
<td>Community hospitals</td>
<td>Community re-ablement teams</td>
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<td>Multidisciplinary assessment clinics</td>
<td>General Rehab. Units</td>
<td>Respite Care Units</td>
<td>Links with Leisure Centres</td>
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<td>Inpatient</td>
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<td>Links with voluntary organisations</td>
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<td>Outpatient</td>
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<td>Links with Work places</td>
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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.
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

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

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, had a vision to offer adult rehabilitation services 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 weekly for landscape reviews, and as a result of this approach a full-time (1.6FTE) position was set within an occupational therapy and physiotherapy to provide adult rehabilitation.

Action

In 2000, a business case for funding was assumed which transformed the service into a specialist nursing and therapy team for people with progressive neurological conditions. The provision of care was made across the local adult community and the current service operates across nine Staffordshire authorities as well as the areas of Cannock, Cannock Chase, South Staffordshire, Telford and Wrekin, and Sandwell.

Using the Staffordshire and Stoke on Trent Partnership NHS Trust ‘Adult Ability’ team, services of care for people with physical conditions, which are difficult to manage and can be very challenging, range from cognitive challenges, physical difficulties, and difficulties with daily living, to more complex conditions such as Parkinson’s disease, multiple sclerosis, Huntington’s disease and Motor Neurone disease. The team provides care in a community setting, focusing on helping patients to remain independent and achieve their goals.

Self-management is key to the philosophy of care provided by the team and their key remit is to

- Person-centred assessment and treatment (physical, cognitive, psychosocial, and emotional)
- Prevention and management - rehabilitation targeting neurological impairment with the goal of improving function or maintaining existing function
- Communication strategies - changing approaches, techniques or behaviors to accommodate patients and reduce difficulties
- Environmental modification
- Encouraging participation
- Life style management
- Working with other services - community and voluntary

This service operates Monday to Friday 9am to 6pm, allowing for access to occupational therapists, physiotherapists, and other specialists. The team aims to see patients within four weeks of referral, and this is achieved through the coordination of the team and the effective use of resources.

Patients can be seen at their home, in clinic-based settings, or at work, depending on the individual’s needs and what is most appropriate for them. The team also provides a range of support for family members and carers, including education and advice. The team is committed to providing a high-quality service, and staff are trained in best practice and the latest evidence-based interventions.

Impact

- A high level of patient satisfaction
- Improved outcomes for patients
- Enhanced patient autonomy and independence
- Improved quality of life for patients
- Enhanced family and carer support
- Improved staff satisfaction
- Improved service effectiveness
- Improved service efficiency
- Improved service quality

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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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)

Grose et al 2012
e.g. Mobility Clinic
### e.g. Co-ordinated MDT Clinics

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<tr>
<td><strong>AM</strong></td>
<td>Therapy Clinic (OT / PT)</td>
<td>Fatigue Clinic</td>
<td>Physio Clinic</td>
<td>MDT Clinic</td>
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<td><strong>PM</strong></td>
<td>FES Clinic</td>
<td>Relapse Clinic</td>
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Linked to & audited against NSF & NICE Guidelines
The Integrative Model of Functioning and Disability

Health Condition

Body Functions
Body Structures

Activities

Environmental Factors

Personal Factors

Contextual Factors

Participation
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
Starting point

Monitor your symptoms

Have you experienced a sudden increase in symptoms over 1-2 days lasting for more than one day?

Yes  Contact your GP / MS Nurse. For specific mobility problems also contact your physio

No

Have you experienced other noticeable changes in your abilities that you would like assessment or advice on?

Yes  Contact your physio

No

From South Devon Health Services Physiotherapy Department Leaflet
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
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

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

![Bar chart showing publications over years](image)

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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%

Review article
The safety of exercise training in multiple sclerosis: A systematic review
Lara A. Pilutti, Matthew E. Platta, Robert W. Mod, Amy E. Latimer-Cheung

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

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<thead>
<tr>
<th>Muscle strength</th>
<th>Muscle mass</th>
<th>Muscle activation</th>
<th>Aerobic capacity (VO2-max)</th>
<th>CVD risk</th>
<th>Depression</th>
<th>Fatigue</th>
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<th>Daily activity level</th>
<th>Functional capacity</th>
<th>Balance</th>
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Red arrow = Impaired in MS patients
Green arrow = Improved after exercise in MS patients

**Slide from Dalgas, RIMS 2014**

Motl & Pillutti, Nat Rev Neurol; Sep;8(9):487-97.2012
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)
Resistance Exercise: 2-3 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.
Reduced speed
• Shorter strides
• Prolonged double limb support phase
• Altered muscle activity and kinematics
• Skeletal changes

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

Slide from Tania Burge / BrAMS / October 2014
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)
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
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:

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).

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

- 6 week 90-minute 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-management & 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 essential ....but 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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