Enhancing Physical Activity and Quality of Life in People with Severe Physical Disability: Could Standing Frame Programmes Help?

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Outline of talk

• Related to people with MS
• Why increase physical activity?
• What’s the evidence for standing programmes?
• Our research: The SUMS Study

Could Standing Frame Programmes Help?

'RESEARCH WITH PLYMOUTH UNIVERSITY'

Freeman/London ACPIN/May2016
Lowered physical activity level


Inactivity worse when progressive > relapse remit using objective versus self report measures. Using more sophisticated physical activity measures.

SPECIAL COMMUNICATION

Development of Evidence-Informed Physical Activity Guidelines for Adults With Multiple Sclerosis

Amy E. Latimer-Cheung, PhD, a Kathleen A. Martin Ginis, PhD, b Audrey L. Hicks, PhD, b Robert W. Motl, PhD, c Lara A. Pilutti, PhD, b,c Mary Duggan, d Garry Wheeler, PhD, e Ravin Persad, BASc, f Karen M. Smith, MD g,h

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

NICE National Institute for Health and Care Excellence

Multiple sclerosis

management of multiple sclerosis in primary and secondary care

Issued: October 2014
NICE clinical guideline 185
Guideline Recommendations: for people with mild to moderate MS

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

**Aerobic Exercise:**
2-3/week
mod intensity (60-80% max HR) 30 minutes minimum 4 weeks
Natural History of MS

An estimated:

• 66% move to a progressive phase within 8 years

• 50% are unable to walk unaided in 15 years

• 25% will become dependent on a wheelchair:
  o Difficulty changing positions
  o Maintaining activity levels
Relative dearth of evidence in those with: progressive forms of MS severe disability (> EDSS 6.5)
Regardless of time spent in formal exercise, spending prolonged periods in sitting can contribute to premature morbidity and mortality.
In people with MS ....

↑ incidence of:
- Osteoporosis (Cosman 1998, Dobson 2013), and associated fractures (Bhattacharya 2014)
- Depression (Zorzon et al 2001)
- Fatigue (Petajan & White 1999)
- Cardiovascular diseases (Bronnum-Hansen 2004, Jadidi 2013, Motl 2011)

There is:
- ↓ aerobic capacity (maximal O2 consumption) (Mostert et al 2002)
- ↓ muscle activation, mass and strength (Dalgas 2008)
- conflicting info re ↑ resting HR, ↑ diastolic blood pressure (Anema et al 1991, Pepin et al 1996)

Co-morbidities are higher in those in the progressive phase of the disease (Marrie 2010, 2013 2015; Simpson 2014)
Impact of prolonged sitting in MS

25% of people with MS spend much of their day sitting

↓

2° complications
(potentially reversible)

↓ quality of life

Physical problems

Weakness, pain, spasms, muscle / joint stiffness, constipation, chest infections

Psychosocial problems

Depression
Lower self esteem
Self identity issues

Significant economic costs:

- ~ 15% of pwMS develop pressure sores (costs of a single sore range from £1,064 (grade 1) to £24,214 (grade 4)).
- Average cost per wheelchair dependent patient is 4–5 times > ambulatory patient.
- Significant ↑ in emergency hospital admissions in people with progressive neurological disability, including MS.

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Managing these issues is a key goal of therapists:

But....

• How difficult is it to achieve this in people who have precarious balance / difficulty walking to go to local gyms or exercise classes?
• Do you struggle with designing exercise programmes to suit their needs?
• How easy is it for people to undertake the exercises you prescribe them?
• Do they/ their carers struggle undertaking them regularly and over the long term?
• How much time is spent sitting down?
• .....even when they are exercising!
Effective self-management strategies are needed....... but challenging

Could use of a standing frame programme within a self-management programme at home be a potential option for addressing this?
Pilot cross-over pilot RCT
Home based standing 30 min/daily/3weeks versus exercise programme
Participants: n=6, >EDSS7.0, 2° progressive MS
Outcomes: spasticity, spasms, range of motion LL joints (0.3.6. weeks)
Results: in standing groups sig ↑ hip and ankle ROM (p<0.05) ; trend ↓ spasticity and spasms
What’s the evidence? (2)

Disability and Rehabilitation

A pilot mixed methods investigation of the use of Oswestry standing frames in the homes of nine people with severe multiple sclerosis

W. A. Hendrie¹, M. J. Watson², and M. A. McArthur²

¹MS Centre, Iceni Court, Norwich, UK and ²School of Allied Health Professionals, University of East Anglia, Norwich, UK

- Mixed-methods approach:
- 9 in-depth single case studies (ABC design)
- 6 women, 3 men; Using wheelchair as predominant means of mobility; Able to be assisted into standing position
- Regular standing over 1 year, 30 minutes/3x weekly
- Stat. sig. improvements in strength, ADL, spasms (p<0.05) (but not pain, bowel frequency)
- Subjective improvements in continence, clonus and fall rate
Hendrie et al 2014: Qualitative component

Phenomenological perspective: lived experience of standing

In-depth interviews at three time points with 9 participants (n=27) over the year

Overarching findings:
The programme reinstated a sense of belonging and optimism by restoring important life roles, a sense of achievement and feelings of normality

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Regaining Skills

“You feel as if you are doing something to make it better, you are more in control” (John)

Changed Body, Changed Mind

“When you are sitting you get shorter and shorter…but when you stand up you feel proud and great again...” (Frances)

Relationship Roles

“I know I can’t go out much now, suddenly I can go up and I’m part of it anyway” (Louise)

Optimism for the Future

“When you stand and achieve things, the feel-good factor overspills emotionally and you start to feel good about other things, so you start to plan other things.....” (Sue)
**What’s the evidence (3)**

**Disability and Rehabilitation: Assistive Technology, 2012; Early Online: 1–9**
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ISSN 1748-3107 print ISSN 1748-3115 online
DOI: 10.3109/17483107.2012.678031

**ORIGINAL RESEARCH**

**On an equal footing: adults’ accounts of the experience of using assistive devices for standing**

Birgitta Nordström¹,², Annika Näslund² & Lilly Ekenberg¹

**Aim:** to illuminate the meaning that standing holds for persons who use standing devices

**Approach:** phenomenological/hermeneutical; in-depth interviews n = 15 (7 progr; ? n = MS)

All had been using standing devices (tilt tables, standing frames, standing wheelchairs) > 1yr

**Overarching findings:**
- the upright body position opens up an opportunity for connection to the outside world.
- has both physical and psychological benefits
- may be something that unites the body and self.
| **Alters the Person’s Sense of Self** | Standing creates the sensation of having a living body. It gives a feeling of the body being in training & standing, to do what one could for one’s body. “...but it becomes another thing, then I am not as insignificant... I become more like others, it is more normal.” |
| **Augments the Person’s Availability to the Outside World** | Standing opened up the sensation of independence and provided the opportunity to look at the world with new eyes. ‘Oh is it here, at this height, that it all happens,’ where I was before... nowadays you see everything from below. All of a sudden I was a normal person! |
| **Strengthens Social Interplay** | “I think that collaboration works better when one is standing up; it is obvious, when one is lying down... you can’t collaborate...” |
| **Changes a Person’s Motivation and their Expectations over Time** | Standing was a way to ensure that one’s body would be able to cope with what the future would bring. |
What’s the evidence? (4)

80% of pwMS have ↑ in muscle stiffness due to passive stiffness and/or spasticity.

Methods
- Lab-based study
- Joint position measured using 3D motion analysis
- Applied force by torque transducers.
- Slow (5o/s) & fast (170o/s) stretches applied via a motor to measure stiffness

Results: duration and magnitude of force required to ↓ stiffness in hypertonic LL muscles was only achieved in supported standing position with greater disability

Marsden, Ofori and Freeman 2013
What’s the evidence? (5)

The effect of supported standing in adults with upper motor neurone disorders: a systematic review

Meredith Newman and Karen Barker

Static frames and tilt tables

Methodology:
• 17 RCT’s (SCI, ABI, PD, CP, Stroke, MS)
• n = 540 participants, 73% non-ambulant
• One pilot RCT in MS (Baker [2007])
Newman et al 2012: What were the effects of standing?

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number of studies / 17</th>
<th>Improved Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spasticity</td>
<td>9/17</td>
<td>7/9</td>
</tr>
<tr>
<td>Range of Movement</td>
<td>7/17</td>
<td>5/7 *</td>
</tr>
<tr>
<td>Bowel function</td>
<td>7/17</td>
<td>5/5</td>
</tr>
<tr>
<td>Bladder function</td>
<td>4/17</td>
<td>4/4</td>
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<tr>
<td>Spasms</td>
<td>4/17</td>
<td>3/4</td>
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<tr>
<td>Weakness</td>
<td>2/17</td>
<td>2/2</td>
</tr>
<tr>
<td>Activities Daily Living</td>
<td>2/17</td>
<td>2/2</td>
</tr>
<tr>
<td>Posture</td>
<td>2/17</td>
<td>2/2</td>
</tr>
<tr>
<td>Respiration</td>
<td>2/17</td>
<td>2/2</td>
</tr>
<tr>
<td>Pressure Ulcers</td>
<td>2/17</td>
<td>2/2: 17% &amp; 37% improved</td>
</tr>
<tr>
<td>Pain</td>
<td>1/17</td>
<td>32% improved</td>
</tr>
</tbody>
</table>

Conclusions: more robust evidence is required
SuMS
Standing Up in Multiple Sclerosis

A multi-centre randomised controlled trial to assess the effectiveness and cost effectiveness of a home-based self-management standing frame programme plus usual care versus usual care in people with progressive MS who have severely impaired balance and mobility.

Investigators: J Freeman (CI), W Hendrie, L Jarrett, A Barton, S Creanor, A Hawton, J Marsden, J Zajicek

National Institute for Health Research

Freeman/London ACPIN/May2016
Aims of SUMS study

Primary aim
• to assess the clinical and cost effectiveness of the home-based standing frame programme plus usual care versus usual care

Secondary aim
• to qualitatively explore the impact of this programme from the perspective of the person with MS and their carer
Objectives of SUMS study

1. Assess clinical effectiveness in improving motor function (primary outcome) and quality of life.
2. Assess clinical effectiveness in improving balance, muscle strength, joint and muscle range, painful spasms, respiratory, bladder and bowel function, number of falls (secondary outcomes).
3. Establish cost effectiveness
4. Explore the subjective experience of using a standing frame within the home (pwMS and carer perspective).
SUMS Trial Design

• Pragmatic multi-centre RCT with blinded outcome assessment and full economic evaluation.

• 3 year study
• 140 people with progressive MS
• Standing programme over 20 weeks plus 16 week follow up
• Blinded assessments by research therapist at local centres: 0, 20, 36 weeks
• Audio diaries 20 people throughout study
Participant information sheet given to participant

Telephone screening to:
- Check entry criteria
- Arrange an appointment for assessment

**Week 1**
- Opportunity to ask questions
- Consent
- 60 minute baseline assessment by independent assessor
- Random Allocation to intervention/usual care group

**Weeks 1 – 20**
**Standing Frame Group**
- Standing Frame ordered and delivered
- Two NHS physio. sessions set up the standing programme
  - Standing 3x weekly for 30 minutes (20 weeks)
  - 6 telephone calls by physiotherapist to check progress
    - Monitoring of adverse events
    - Audio diaries (sub set)

**Week 20**
60 minute baseline assessment by independent assessor
Continue with usual care/standing programme

**Weeks 1 – 20**
**Usual Care Group**
- Continue with usual physiotherapy and healthcare
  - Monitoring of adverse events

**Week 36**
60 minute baseline assessment by independent assessor
End of study

**Fidelity Checking**
8 Study Centres

1. Torbay and Southern Devon Health and Care Trust
2. Northern Devon Trust
3. Livewell South West (nee Plymouth Community Health)
4. Royal Devon and Exeter NHS Trust
5. Cornwall Partnership NHS Foundation Trust (CFT) (nee Peninsula Community Health)
6. Norfolk Community Health and Care Trust
7. Suffolk Community Health and Care Trust
8. East Coast Community Health Care CIC

Each site has on average seven teams involved in delivering physiotherapy within the community
SUMS: Where are we now?

As of 14.5.16
55 participants:
• 28 South west
• 27 East Anglia

If you know of any other people with MS who may be interested in participating in this study, please do let us know.

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SUMS Study Web-site
www.plymouth.ac.uk/research/sums
Summary

• People with progressive MS generally lead sedentary lives, and find it difficult to increase their activity levels. As physio’s it can be very challenging supporting them to change this.

• Preliminary evidence suggests supported standing:
  • help to confirm and build a person’s trust in his/her body and self
  • may have positive physical outcomes for people with progressive MS who have severely impaired balance and mobility

• No evidence to date looks at cost effectiveness

• Watch this space for more definitive evidence (2018) on the SUMS Study Web-site www.plymouth.ac.uk/research/sums
2. Heesen C et al. Patient perception of bodily functions in multiple sclerosis: Gait and visual function are the most valuable. Multiple Sclerosis 2008; 14:998–991.
12 Nordström B et al. On an equal footing: adults’ accounts of the experience of using assistive devices for standing. Disability and Rehabilitation: Assistive Technology, 2012; Early Online: 1–9
Thank you for listening: any questions?

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