

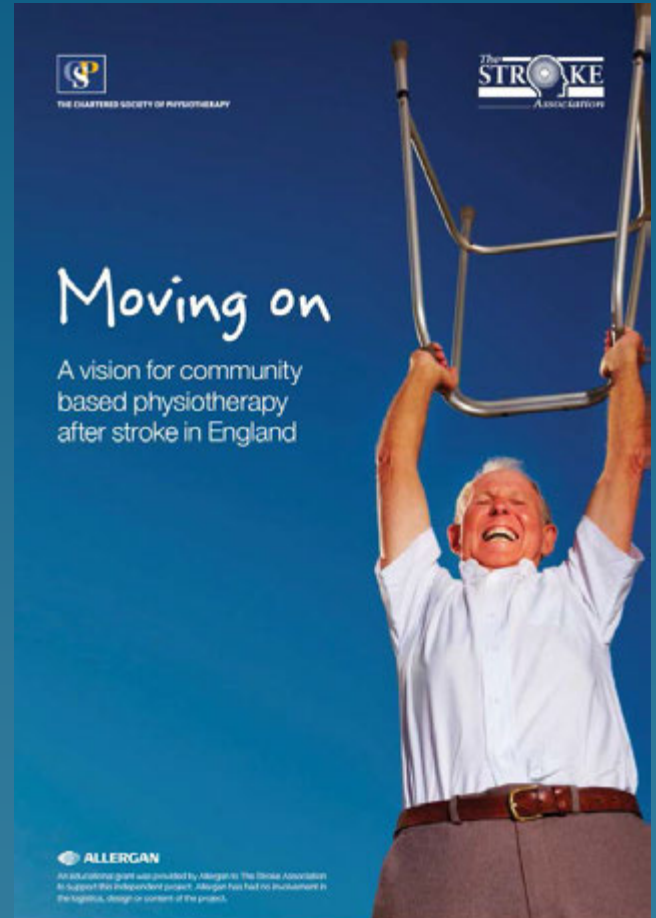
What do we mean by Self-Management?

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Beyond therapy

- **People with stroke**
 - *feel abandoned*
 - *don't feel prepared to self-manage*
- **Rehabilitation professionals**
 - *think outcomes could be improved in about 50% of patients*
 - *believe they prepare people for life beyond therapy*





How well do we train and prepare people for the hard work of self-management?

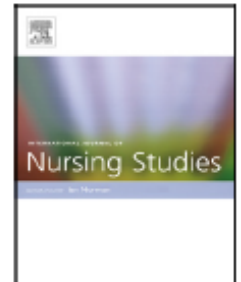




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Stroke self-management: A focus group study to identify the factors influencing self-management following stroke



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ABSTRACT

Background: Self-management refers to the strategies, decisions and activities individuals take to manage a long-term health condition. Self-management has potential importance for reducing both the personal and health service impact of illness. Stroke represents a significant health and social burden, however there is a lack of clarity about the factors that

Boger et al, 2015, Int J Nurs Stud, 52, 175-187

Health Warning



...you may not like what you hear

Trying hard

I think we all, we all do more than they [Healthcare Professionals] expect. We do try hard, though they think we don't.

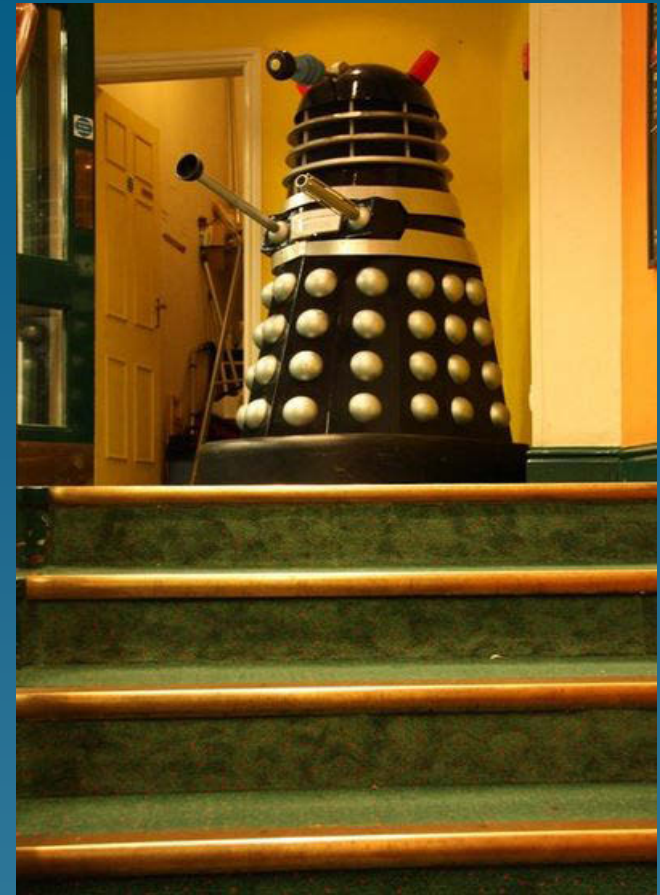


(Un)Supported self-care

- *I think that's one of the biggest problems actually [for self-management], coz when you first have your stroke there's loads of help (Nathan)*
- *yeah, and then you get kicked out (Frances)*
- *you get kicked out basically, that's it, isn't it? (Nathan)*
- *yeah (Frances)*



Managing Alone

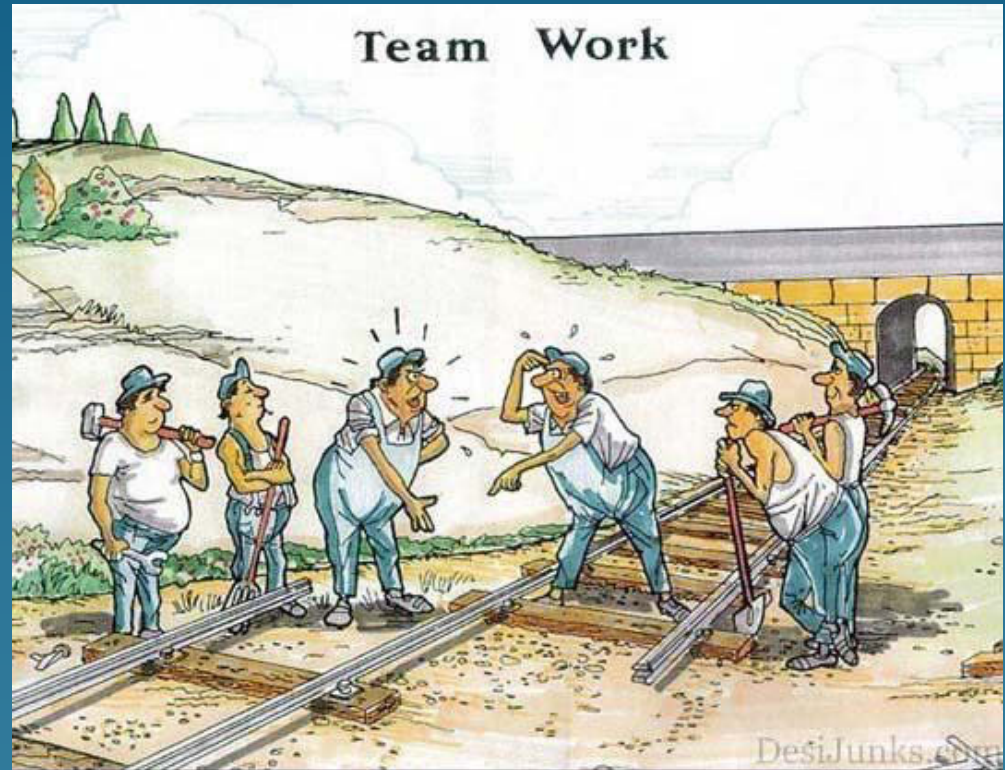


I can go on myself all I like, it's kick-starting other people that I find a problem with. You know, I just feel like I've got to a dead-end, and not through any fault of my own

No clear plan

*there should be a plan,
and everyone should
understand their part
of the plan.*

*It shouldn't be up to
me [points to self], as
the patient to have
the plan in my head,
which is what
happens.'*



Not in everyday language

what they tend to do, when you come out of hospital, they give it [information] to you on paper, and they give you the names, the proper names of what's happened to you....and it's so [pause]....you don't really understand it.....if it was in everyday language...I think a lot of people leave the hospital not fully conversant with what's happened to them. I mean they talk to you, but [pause]can you take it in?



informational conflicts

- *you get told one thing by one therapist, [sighs] another thing by another therapist*
- *yeah*
- *they don't sing from the same hymn sheet*
- *Conflicting isn't it?
Everything's conflicting*



Don't know why?



You know how important it is to keep doing things.... coz they [HCPs] just tell you to do it....but they don't tell you why.

Doing more harm than good?

She does all this stuff herself, but often it will really hurt...perhaps a physio could say 'do it like this' or whatever, but instead she doesn't know how far to go and she ends up over-doing it and having tendonitis or some associated thing when really you need the guidance. She could be laid off for a few weeks and go backwards.

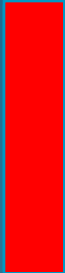
Physiotherapy



recommended

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Stroke



Rest of life



Rehab

*Patients and carers
managing alone*



What do people need to self-manage ?





Southampton stroke self-management questionnaire ©

- *Developed from perspectives of people with stroke*
- *Content and wording cognitively tested with people with stroke*
- *Measures self-management attitudes, behaviours and skills – individual capacity*
- *Psychometric evaluation with 89 people with stroke: Valid and reliable*

	Always true	Mostly true	Somewhat true	Somewhat false	Mostly false	Always False
16. I plan my day so I can get things done without being tired						
17. I feel confident asking family members to help me do things important to my health						
18. I manage things related to stroke as well as other people with stroke						
19. I try different ways of doing things, until I find out what works for me						
20. Ideas and things that work for other people with stroke are helpful to my recovery						
To use the SSSMQ for clinical or research contact: shd@soton.ac.uk						

Therapists' experience of supporting SM

Normal Practice = Benign Dictatorship

- *Commitment to patient good*
- *Therapists in control – set agenda*
- *Therapists should be and are the experts*
- *Passive patients - exacerbated by acute care*
- *Organisational agenda – safety and discharge*

Therapists supporting SM

Supported Self-Mgt = Reluctant Democracy

- Training patients – to ‘find their own solutions’ – ‘be in the driving seat’
- Meaningful activities are central to therapy
- Supported the philosophy
- Challenges
 - ‘unsuitable’ or ‘unsafe’ tasks; patients without goals; letting go of power; not enough time; counter to organisational culture

Self-Management

- *“individuals making the most of their lives, coping with difficulties and making the most of what they have...doing what they can do to feel happy and make the most of their lives despite the condition”
(Department of Health, 2008)*
- *Its what people with LTCs are doing all of the time: to a lesser or greater degree; with more or less skill; with more or less support; with better or worse outcomes
(Demail)*

Self-management continuum



Very little or no understanding of what is done to them, no emotional buy in or commitment. No or ad-hoc cooperation

Able to set ambitious goals, commit to them despite difficulties, & take initiative to achieve them

Self-management: it's not "yes" or "no"

(Roy Batterham 2010)

Some capacity to express aspirations and wishes and understand health implications. Willing to participate in health decisions but easily swayed off track and has difficulty maintaining personal effort.

Comatose, or equivalent.
Has 'stuff done to them'

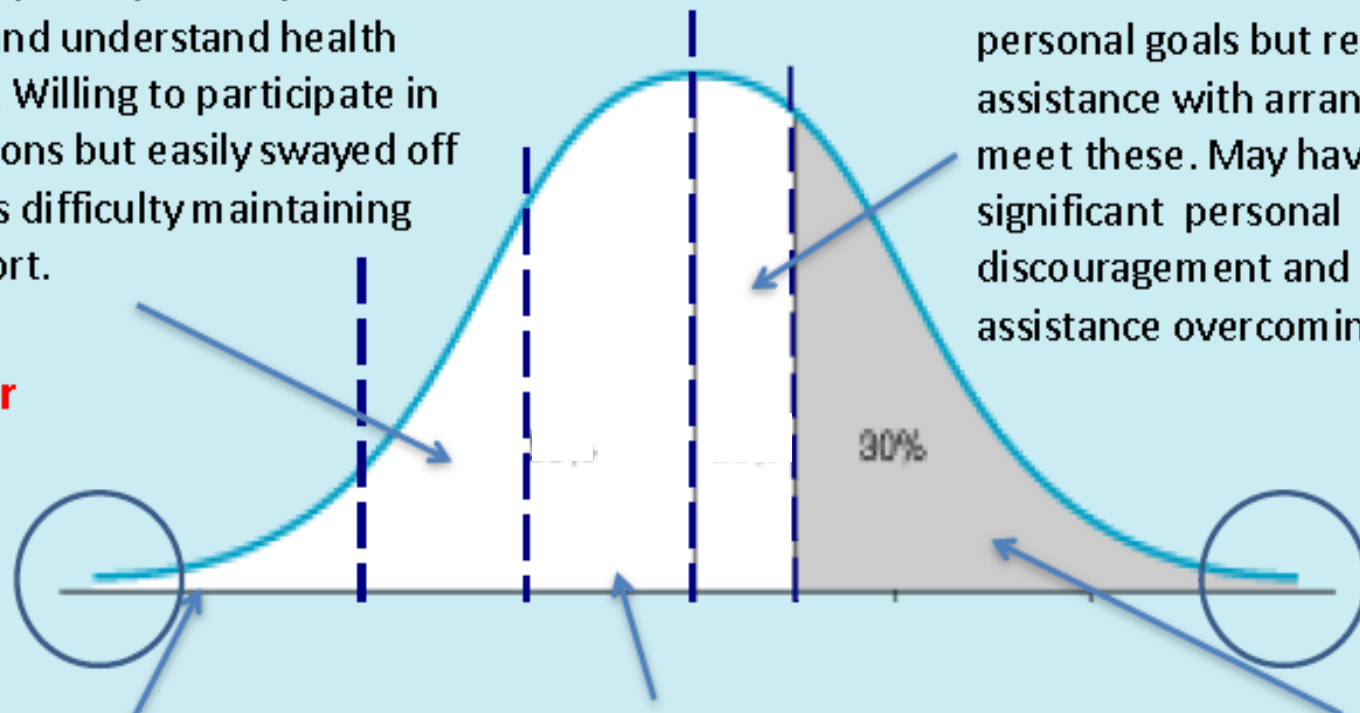
Very little understanding of what is done to them and no emotional buy in or commitment. Cooperation ad hoc and reactive if at all.

Able to express wishes and preferences and understands how health services and personal actions can contribute to these. Actively participates in health service decisions and cooperates to the best of their ability. Piecemeal approach to personal health care actions

Able to set and commit to personal goals but requires assistance with arrangements to meet these. May have periods of significant personal discouragement and require assistance overcoming setbacks

Health and fitness fanatics

Able to set goals and commit to them and take initiative in accessing the means to achieve them)



‘Good’ self-management?

Fending for yourself



OR

Knowing when to
access support?



Helping health professionals to help patients to help themselves



Skills for Care, Skills for Health - Common core principles to support

<http://www.skillsforcare.org.uk/>

Could we support self-management better?

- Teach people how to set goals?
- Teach people how to monitor progress and evaluate success?
- Build in strategies to build confidence and self-efficacy?
- Provide appropriate information and teach people how to access information?

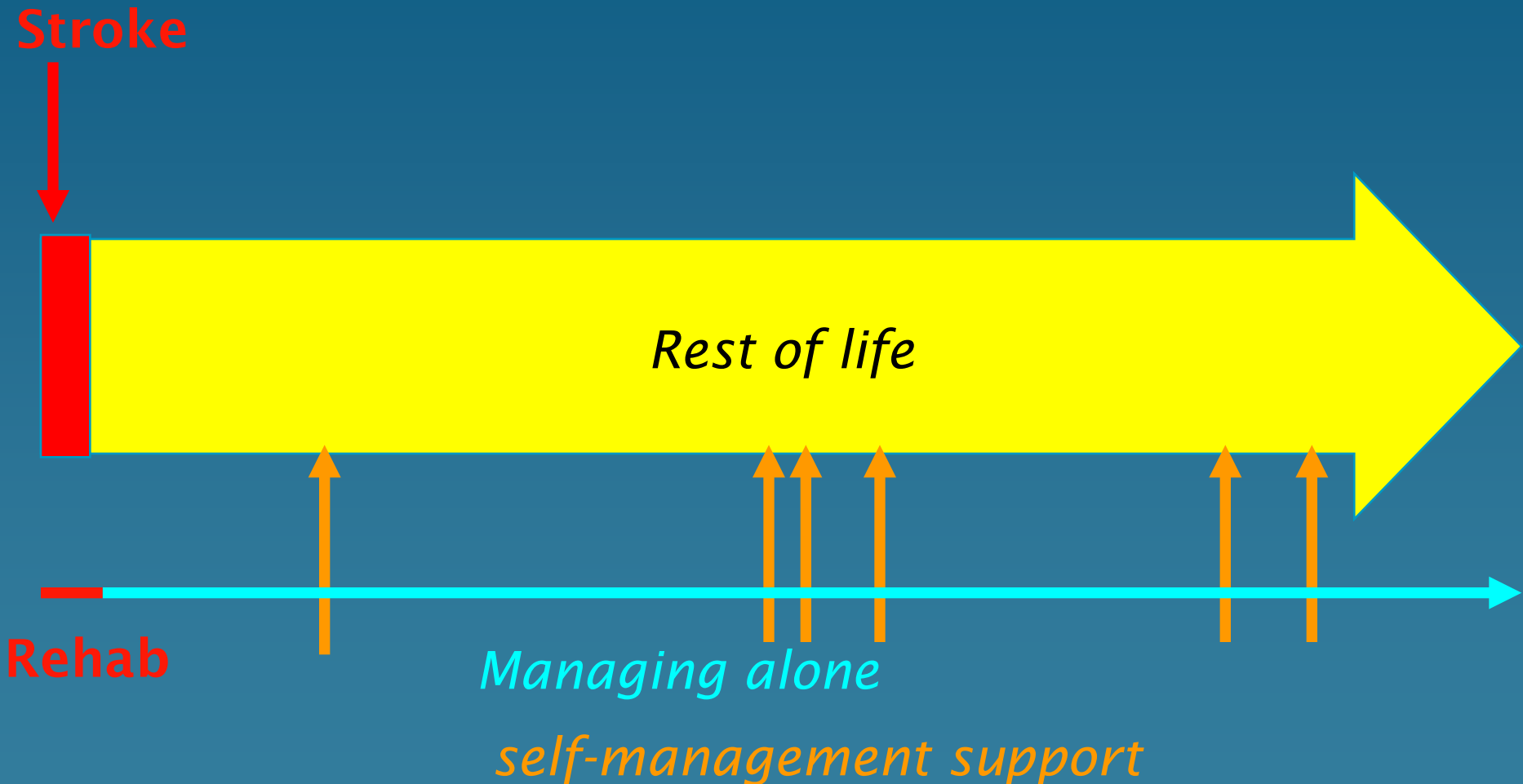


Could we support self-management better?



- Introduce people to appropriate support networks ?
- Introduce people to appropriate exercise facilities?
- Discuss risk and teach people how to assess risk?
- Provide opportunities for self-referral?
- Refer to local SM courses ?

Can we change the experience of stroke self-management



What would need to change?

- *Do we*
 - *have enough knowledge about SM?*
 - *have skills to support SM?*
 - *know what resources are available locally for SM support?*
 - *know what resources are available on-line?*
 - *need to change our emphasis during rehab?*

Plan

- *What one thing do you want to do next to improve the SM support you are able to give*
- *Set yourself a goal for one thing you will do in the next 6 months to improve SM support in your work / service.*

Self-Management VOICED: outcomes that matter



Self-Management VOICED (Valued Outcomes of Importance: Consensus and Disparity)

SMVOICED is a two year Health Foundation funded project, which started in November 2013.

The project is led by a team of researchers from the Faculty of Health Sciences at the University of Southampton, along with colleagues from St George's University of London and the University of Leeds.

The aim of SMVOICED is to identify which outcomes of self-management are considered important by patients, their family and friends, health professionals and commissioners of services (stakeholders).

To achieve this SMVOICED have chosen diabetes, bowel cancer and stroke to act as exemplar conditions.

Want to know more or take part in SMVOICED?

Our Research

The project is split into three distinct phases. Find out more about each phase.

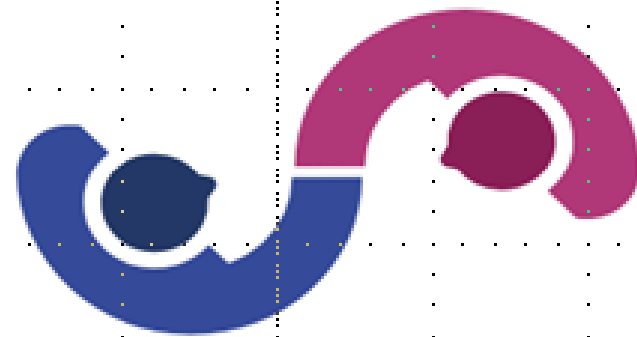
Take Part

We are recruiting for our national survey. Find out if you are eligible to take part. We welcome a range of views, so please contact us.



*To take part in the
survey of health
professionals please
contact Sara*

shd@soton.ac.uk



Supported Stroke
Self-Management Network

www.strokeselfmanagement.org

A community for anyone interested in shaping
stroke self-management research and practice

Register your interest:

www.surveymonkey.com/s/8ZKKVFD

Or follow us on Twitter [@SSMNet](https://twitter.com/SSMNet)