“Mind yourself”
neurological
self-management

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Outline

• Self-management
  • What is it?
  • What's available for people with neuro conditions?
  • Examples?
  • What published research is out there?
  • Anecdotal background about people with head trauma (TBI)
• TBI special issues for self-managing
• Conclusion
What is self-management?
Defining self-management

Self-management involves

“engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes in partnership with health professionals and community resources.”

Self-management

• Patient-centred care
• Patient education

... NICE guidance - patient education should reflect established principles of adult education

Aims
• Improve knowledge, skills & confidence
• Enable increasing control of condition
• Integrate effective self-care into daily lives

To be better biomedically and to improve quality of life and satisfaction
Expert Patients Programme

- Developed from US Stanford Univ model
- UK start with arthritis (as was also in US)
- Other long-term conditions started through the Long Term Conditions Alliance, late '90s
- ... Expert Patients Task Force
- Expert Patients programme, 2002
- EPP Community Interest Company, 2007
- 5,000 courses have been run
- 70,000 participants
- ... a “typical” course might have 8-12 participants, last 6-8 weeks, 2 hrs per week
What's happening for people with neurological conditions?
National Service Framework for Long Term Neurological Conditions (NSF LTNC)

- Launched March 2005 with 10 year implementation timescale
- New Style NSF - no national targets, no ring-fenced money - locally agreed implementation plan and milestones
- Seeking to transform health and social care provision for people with long term neurological conditions (LTNC)
“Halfway through – are we halfway there?”

- MS Society, MND Association, Parkinson’s UK, Neurological Commissioning Support (2010)

“Information: People are not receiving even the basic information they need to manage their condition appropriately. Most services still do not have a single point of contact for people to find information about managing their condition, and access to the services they require. Many people spend significant amounts of time trying to locate information sources or simply give up searching.”
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Independent Overview Report for Dept of Health, March 2012
assessing implementation of NSF LTNC

- 40% felt involved enough in care
- 22% aware of personalised care plan
- 27% had enough support for self-management
- ... + carers’ support issues
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- Variable & patchy services
- Carers' health & well-being negatively impacted in care
- Doubling of service disadvantages by poor communication, information & demand management systems
- Unnecessary stresses & negative effects on mental health
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“We need to know more about ... what people with LTNCs require from self-management programmes that is different from what they get from other generic expert patient programmes.”
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“It is clear from the evidence considered here that people with LTNCs and their carers do not have unrealistically high aspirations or expectations for care and support – they just want to get their lives back.”
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Summary checklist “key question” 1 for planners and commissioners of services -

- “Appropriate and accessible information and advice - how will you ensure that people are kept informed in ways that are right for them?”
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“Key question” 2 -

• “How do you know what local providers and organisations there are locally with the expertise and experience to contribute - e.g. who’s best placed to run self-management, education and peer support and day opportunities?”
What are examples of self-management courses?
Courses

Challenging Your Condition Arthritis Care
Expert Patients Programme EPP CIC - England / Wales
Looking After Me EPP - Scotland
Self-management groups Pain Assoc.Scotland
Lifestyle Management Programme Thistle Foundation
A Path Through Parkinson's Parkinson's UK
Managing the Challenge of Western Health & Living With a LTC Social Care Trust (NI)
Course content example

6 x 2.5 hours, once a week

- My Story
- Making Choices
- Understanding My Condition Better
- Improving Confidence
- Healthy Living
- Accessing Timely Information
What research exists on neurological self-management?
Self-management post-brain injury

Self-management stroke + MS + SCI

Self-management of diverse neuro disorders

Self-management mild TBI (mostly)

Self-management post-stroke just published

Anecdotal background - (some/numerous) people who've had TBIs and may be looking to move ahead
Patterns for positive change?

...starting through peer groups

- 1 Stimulus and enduring social re-engagement begun by helping and supporting other people.
- 2 Stimulus and some social re-engagement made possible by understanding that there are others with similar experiences
- 3 Stable equilibrium, and not frequently set back
Patterns for positive change?

...starting through peer groups

- 4 Goal-reaching changes which can be, for example -
  - “broadly” social, getting on well with people in general
  - “personally” social, with partners / family
  - work (or other) activity which is distinctly structured
Special issues for self-management by people who've had Traumatic Brain Injuries
Unawareness & executive function

Common consequences of TBI

- Absent or limited appreciation of physical, emotional, behavioural, cognitive difficulties
- Passivity / resistance in rehab or in daily life? Non-compliant, resistant to interventions, reluctant to use compensatory ideas
- Impaired planning, goal-setting, problem-solving
Lack of self-awareness

- Lacking accurate information about ourselves and the nature and magnitude of impairments
- Puzzled by feedback about behavioural or functional limitations
- Cautiously willing or indifferent when asked to work along with new information about limitations

Prigitano & Klonoff (1998)
Denial

- Partial or implicit knowledge about limitations
- Resistant or angry when given feedback about behavioural or functional limitations
- Actively struggle to work along with new information about limitations

Prigitano & Klonoff (1998)
Developing a conclusion?
Mind yourself well ...?

- Good self-management assistance for people with neurological conditions needs more & better research

- Condition-relevant innovations need urgently be sought for people (and families) with TBI to self-manage using guiding protocols and assistance

- As a corollary of personal self-management, system management and planning need fresh effective insightful “user” inputs
Thanks for taking part!

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