

"Mind yourself" neurological self-management

Paul Barrett

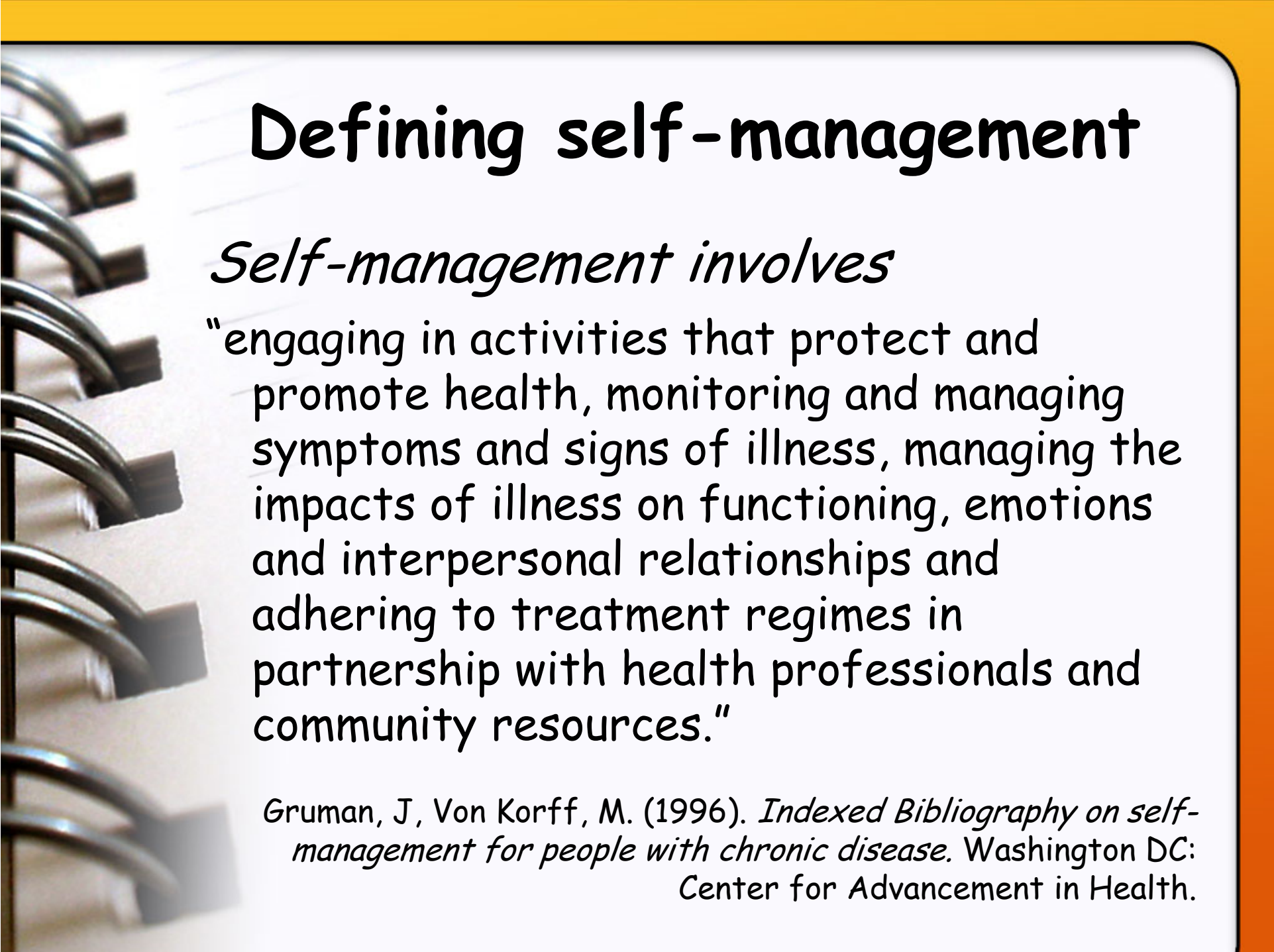
**City University London
Disability & Social Inclusion Seminar
10th December 2013**

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

A close-up photograph of a spiral-bound notebook. The notebook is open to a page with horizontal lines. The metal spiral binding is visible on the left side. The text 'What is self-management?' is written in a bold, black, sans-serif font on the page. The background of the notebook is a solid orange color.

**What is
self-management?**

A spiral-bound notebook with a metal spiral binding on the left side. The pages are white with faint horizontal lines. The notebook is set against a solid orange background.

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."

Gruman, J, Von Korff, M. (1996). *Indexed Bibliography on self-management for people with chronic disease*. Washington DC: Center for Advancement in Health.

Self-management

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

Aims

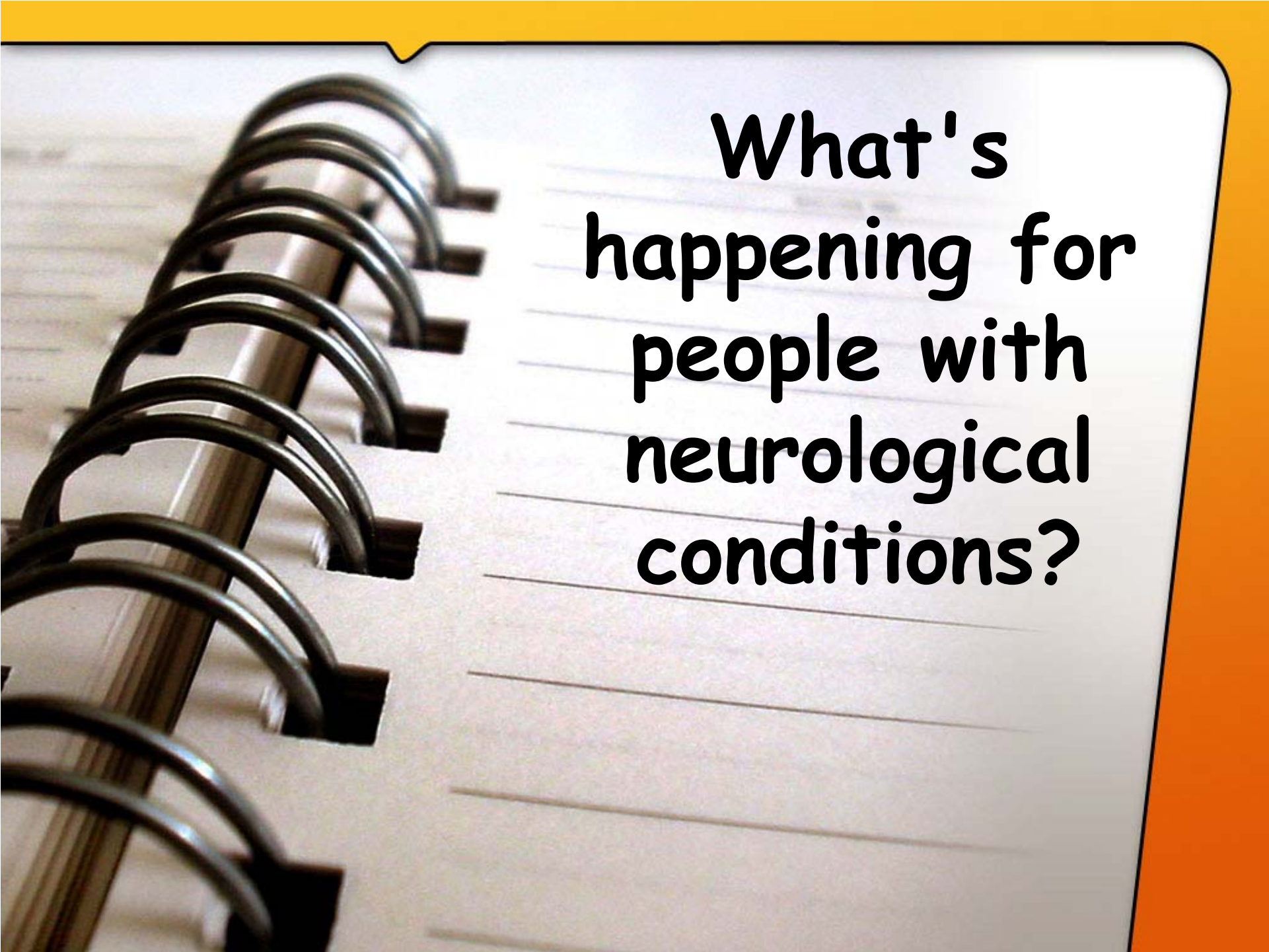
- Improve knowledge, skills & confidence
- Enable increasing control of condition
- Integrate effective self-care into daily lives

To be better biomedically and to improve quality of life and satisfaction

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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

A close-up photograph of a spiral-bound notebook. The notebook is open, showing a white page with horizontal lines. The metal spiral binding is visible on the left side. The text is written in a large, bold, black font. The background of the notebook is a solid orange color.

**What's
happening for
people with
neurological
conditions?**

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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)

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“Halfway through - are we half way 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.”

"A LIFE MORE

ORDINARY"

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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"A LIFE MORE ORDINARY"

- 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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"A LIFE MORE ORDINARY"

"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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"A LIFE MORE ORDINARY"

"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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"A LIFE MORE ORDINARY"

**Summary checklist "key question" 1 for
planners and commissioners of services -**

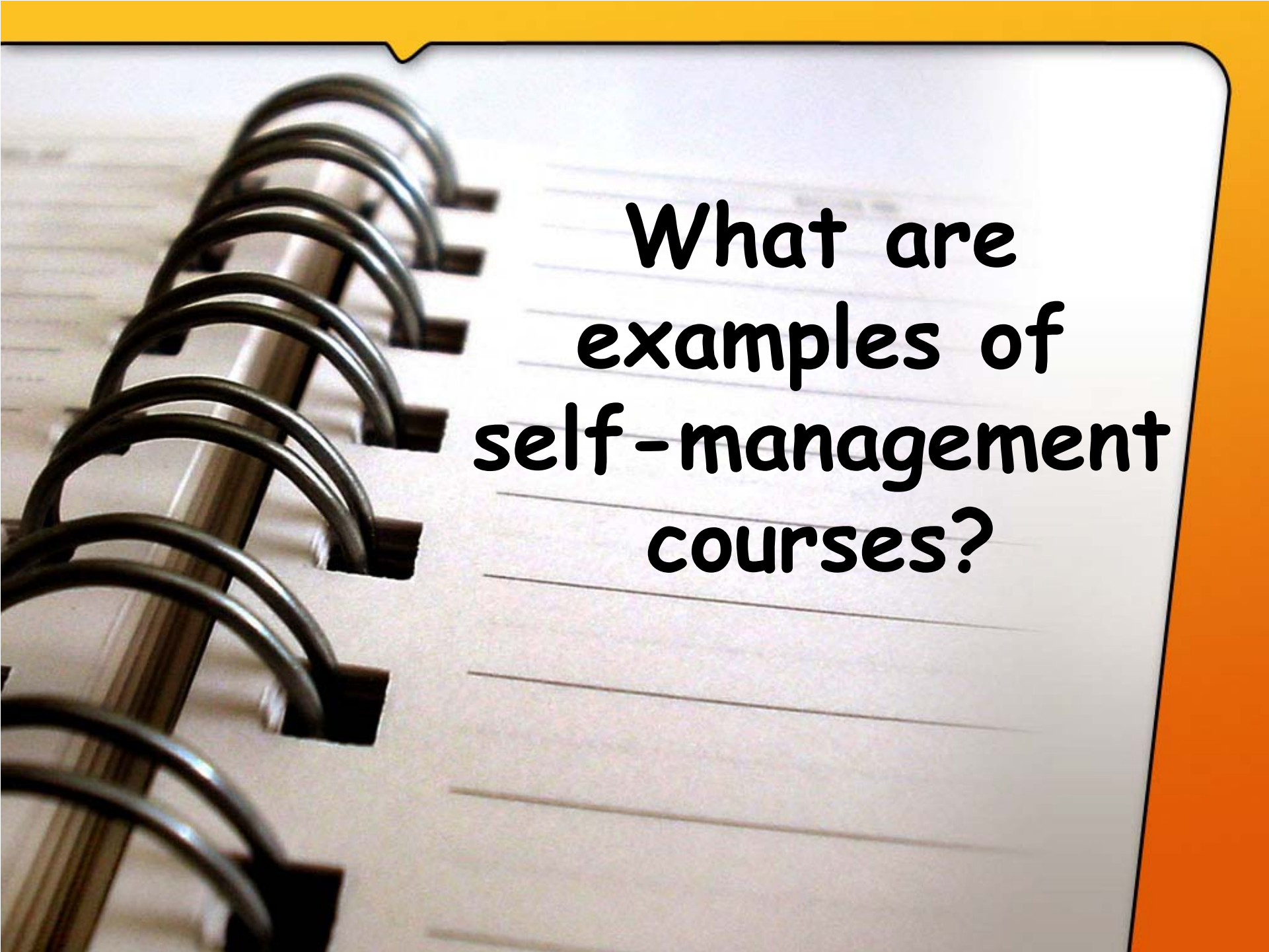
- "Appropriate and accessible information and advice - how will you ensure that people are kept informed in ways that are right for them?"**

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"A LIFE MORE ORDINARY"

"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?"

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**What are
examples of
self-management
courses?**

Courses

Challenging Your Condition

Arthritis Care

Expert Patients Programme

EPP CIC - England / Wales

Looking After Me
Scotland

EPP -

Self-management groups

Pain Assoc.Scotland

Lifestyle Management Programme

Thistle Foundation

A Path Through Parkinson's

Parkinson's UK


**Managing the Challenge of
Living With a LTC**

Western Health &
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**

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**What research
exists on
neurological
self-management?**

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Self-management post-brain injury

- Muenchberger, H, Kendall, E, Kennedy, A, & Charker, J (2011). Living with brain injury in the community: Outcomes from a community-based self-management support programme in Australia. Brain Injury, 25 (1), 23-34.

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Self-management stroke + MS + SCI

- Hirsche, R, Williams, B, Jones, A, & Manns, P (2011). Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. Disability and Rehabilitation, 33 (13-14), 1136-1146.

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Self-management diverse neuro disorders

- Rae-Grant, A, Turner, A, Sloan, A, Miller, D, Hunziker, J, & Haselkorn, J (2011). Self-management in neurological disorders: Systematic review of the literature and potential interventions in multiple sclerosis care. Journal of Rehabilitation Research & Development, 48(9), 1087-1100.

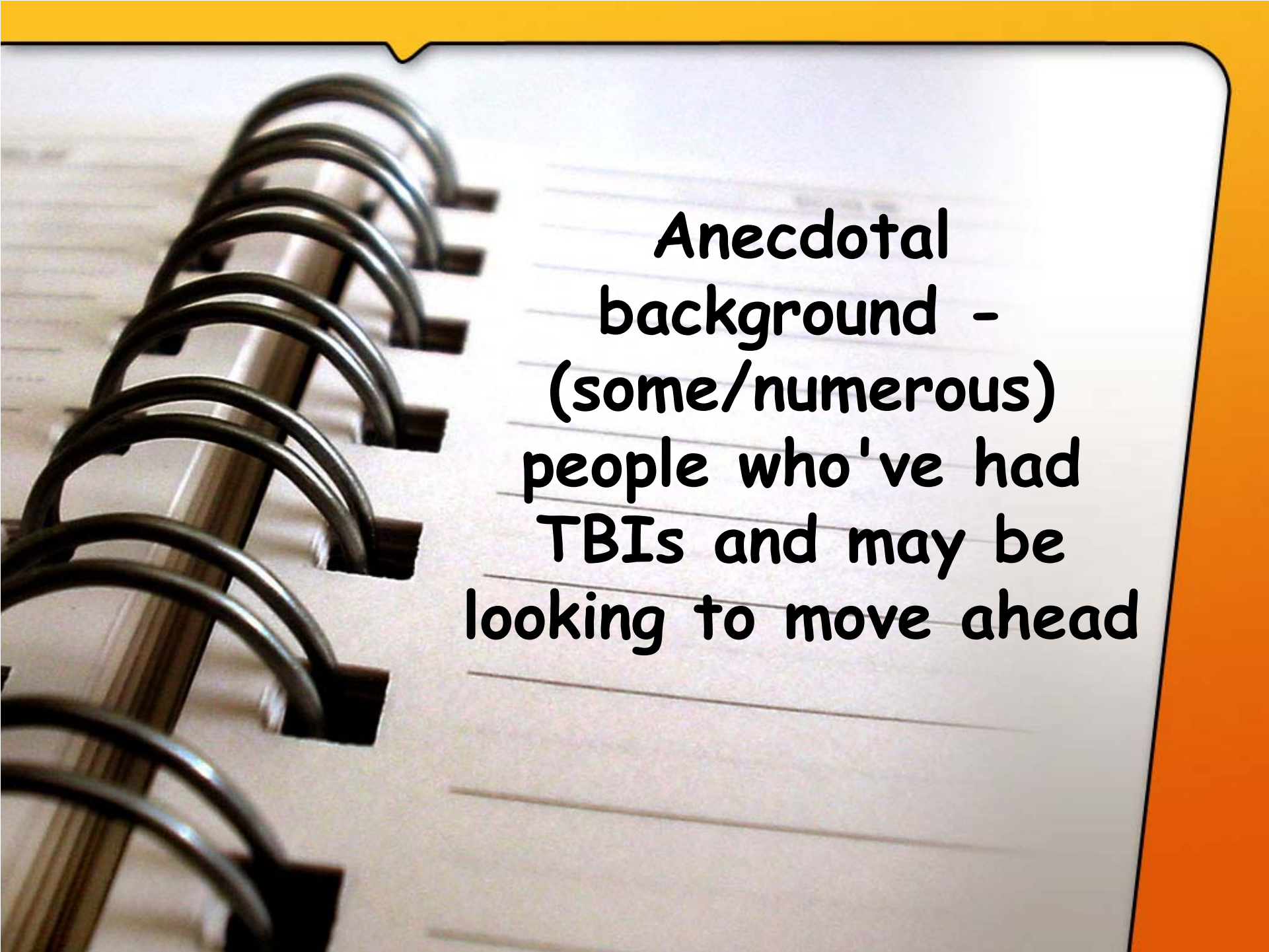
Self-management mild TBI (mostly)

- Kendrick, D, Silverberg, N, Barlow, S, Miller, W, & Moffat, J (2012). Acquired brain injury self-management programme: A pilot study. Brain Injury, 26 (10), 1243-1249.

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Self-management post-stroke *just published*

- Lennon, S, McKenna, S, & Jones, F (2013). Self-management programmes for people post-stroke: a systematic review. Clinical Rehabilitation, 27(10), 867-878.

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**Anecdotal
background -
(some/numerous)
people who've had
TBIs and may be
looking to move ahead**

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Patterns for positive change?

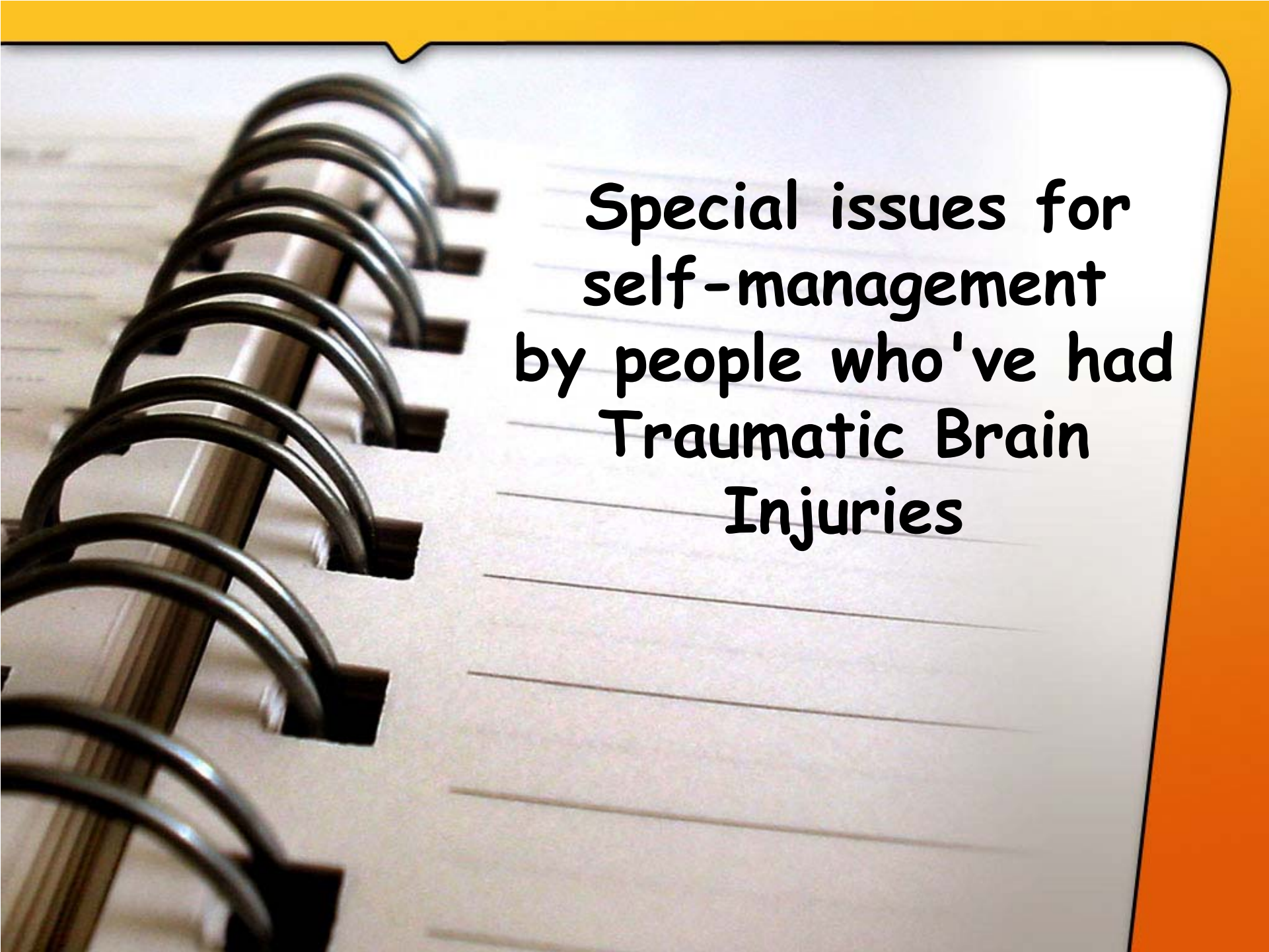
...starting through peer groups

- 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

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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)

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**Developing a
conclusion?**

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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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