Implementing the New Vision for People with Dementia and their Carers

Enabling People with Dementia and their Carers through Technology

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To implement the vision, this presentation will consider:

- Self management for people with dementia
- Rehabilitation for people with dementia; both community living and those in care
- The contribution that technologies and good design can make
The old view of dementia: a dread diagnosis
Unfortunately, people with dementia are sometimes seen as ‘unsuitable for rehab’...This can arise if dementia is seen one-sidedly as a process of degeneration, or if rehabilitation is seen largely in terms of functional performance or simplistic notions of independence....

Wey, 2002, Journal of Dementia Care 10(3)

Other unhelpful connotations still exist......
Downward Spiral: self-fulfilling prophecy

- Low expectations by others
  - further deskilling
  - denial of opportunity to participate in meaningful activities
    - deskilling
    - inability to participate
      - further lowering of expectations
        - more denial to participate in meaningful occupation
          - further deskilling
The new perception: helping people to live a quality life with dementia
“Being told I had dementia was like a door re-opening after a difficult time in my life – new challenges, new opportunities”.

“I want people to understand that dementia isn't an end, it's a new beginning where you do things differently. While some things change forever there is a lot you still can do.”

James Mckillop
Listening to the voices of people with dementia

Rarely articulated and concerns:-

• Retaining personhood: not wanting to be dressed by others

• Fear of confusing a sexual partner with other close relatives

• Incontinence

• Vulnerability in the community
New Ideologies and professional practice in dementia care

• Abilities rather than deficits

• Self management in the earlier stages of the illness

• Promoting rehabilitative potential at all stages

• Quality of life throughout the course of the illness
New ideologies and professional practice in dementia care

- Involvement of the person with dementia at all times with their carer

- Technologies to facilitate self management/independence/enjoyment...

- Implications of the Mental Capacity Act

- Good design of equipment and environments
Reversing the negative spiral

- Early diagnosis

- Assessment, review, reassessment: person with dementia and carer

- Tailored interventions to meet needs

- Information and support
Changing parameters in response to assessed need

Self Management

Restorative
Physical & cognitive

Mild
Impairment

Moderate

Severe

Enabling

Compensatory
Self Management

• In the early stages of the illness following diagnosis
  Mountain (2006), Dementia, The International Journal

• Involving both the person with dementia and their carer

• The Expert Patient Programme has funded the development of a self management training course for people with early dementia which is being piloted by Gail Mountain and Claire Craig
  www.expertpatients.co.uk
Components of the Self Management Programme

- Emotional support
- Pleasure
- Social support
- Managing new challenges
- Memory and daily living support
- Support to maintain health
- Accessing and using available support
Service Requirements

Must be supported by a whole systems approach towards service delivery which:

- promotes early diagnosis and improved access to services
- improves information provision and knowledge
- enables professionals to work within a more flexible, patient centred approach
Changing perceptions of needs for rehabilitation.....

- People with dementia are being included within the remit of intermediate care services in many locations.

- Service innovation is occurring up and down the country.

- Alzheimer Society “Living with Dementia” Programme  [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
Approaches with people with severe dementia

- Cognitive approaches like quizzes and reality orientation are redundant in people with severe dementia
- The playful practitioner: undertaking enjoyable activities
- Weaving rehabilitation into the fabric of care
- A skilled person centred approach

Perrin and May, 2000
Harnessing the potential of technology

Already out there:

• Community equipment/ assistive technology

• Telecare technologies: community alarms, various devices to prevent accidents, SMART homes, sensors etc

Not rehabilitative in themselves: depends upon associated interventions
New applications to promote independence

• Use of mobile phones to prevent getting lost

• Technology tagging to enable others to locate the person

• Technologies to provide reminders and prompts information and assistance
Technology for enjoyment: a new area

- Recall and reminiscence e.g. digital story telling
- Socialisation e.g. social networking
- Comfort e.g. robotic pets
Workers need to embrace the new possibilities presented by technology

This requires:

• Involving users and carers in devising and testing new developments – be sure that people want what is being offered

• The provision of an appropriate infrastructure for technology provision

• “Doing things differently”
Consistent Requirements

• Involvement of informal carers in all settings: community and residential care

• Listening to the views of people with dementia Reid et al, 2001

• Enhanced communication: verbal and non verbal Kitwood, 1993; Allan, 2001

• Person centred care Benson, 2000
Listen to the Voices of People with Dementia

“I'm not dying of dementia. I'm living with dementia.”

“I want to keep going for as long as I can and when things are difficult I don't want to be left on the shelf or forgotten.”