

# Implementing the New Vision for People with Dementia and their Carers

Enabling People with Dementia and their Carers through  
Technology

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SHARPENS YOUR THINKING



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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

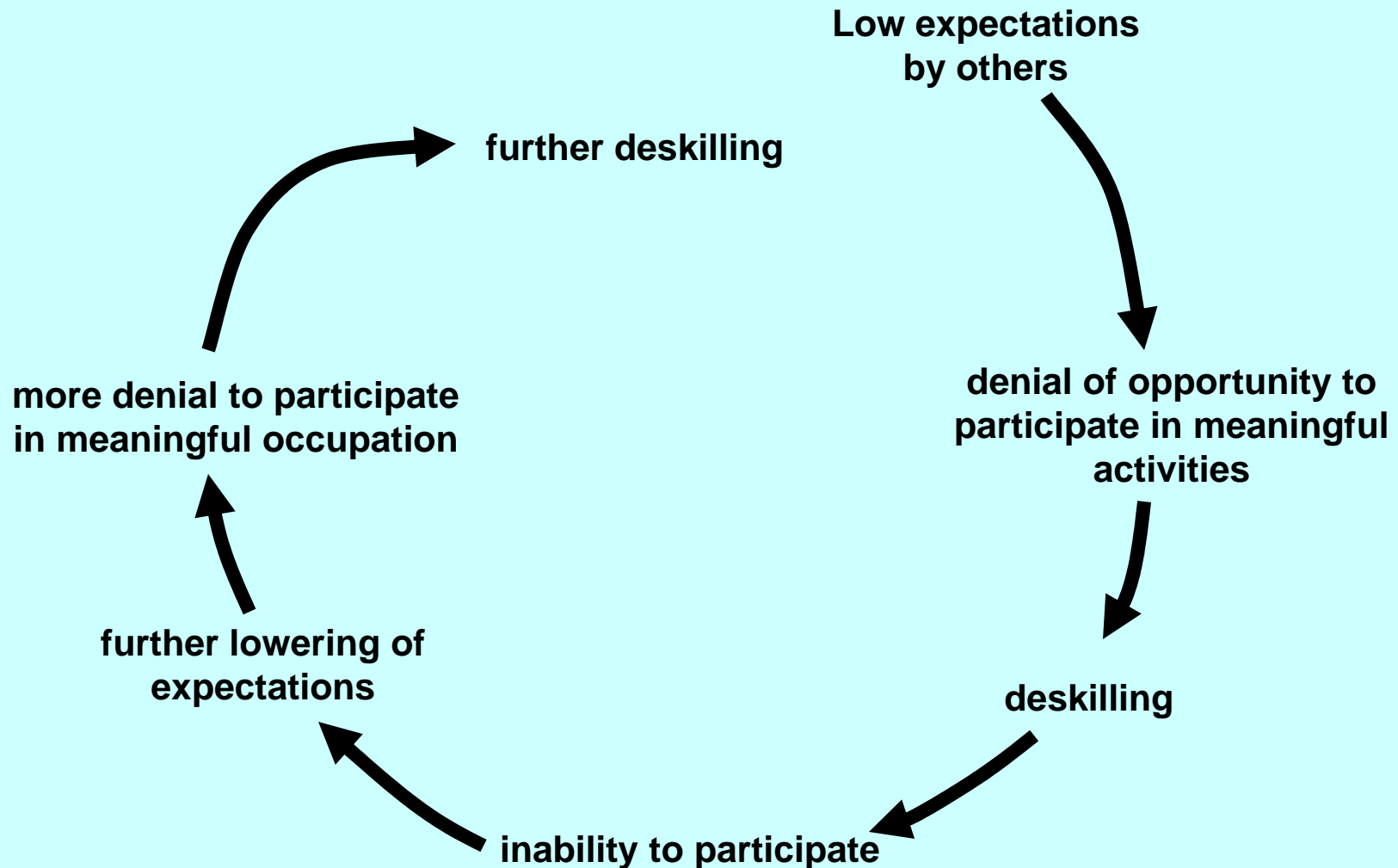


*Unfortunately, people with dementia are sometimes seen as 'unsuitable for rehab'... This can arise if dementia is seen one-sidedly as a process of degeneration, or if rehabilitation is seen largely in terms of functional performance or simplistic notions of independence.....*

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

*Other unhelpful connotations still exist.....*

# Downward Spiral: self-fulfilling prophecy



# **The new perception: helping people to live a quality life with dementia**



# Listening to the voices of people 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

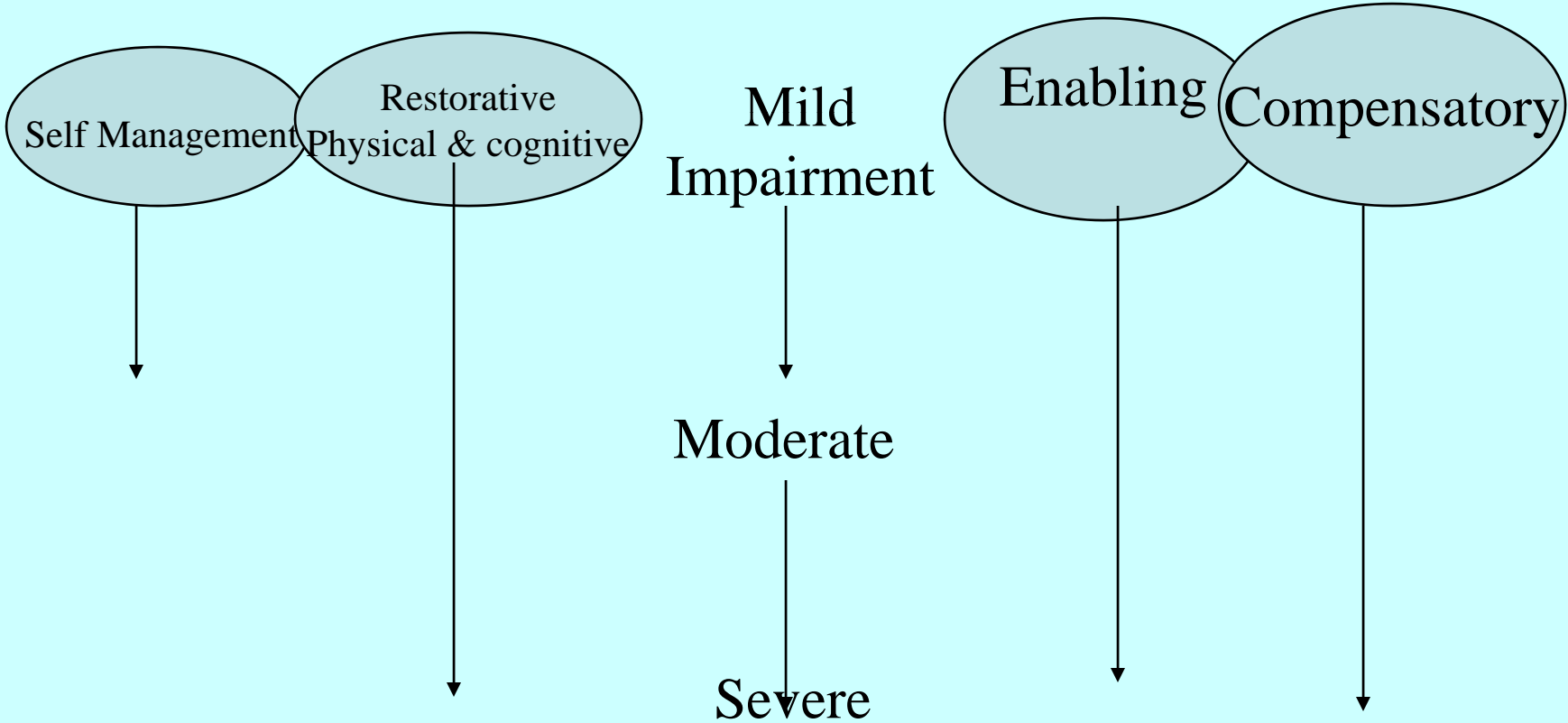
# New ideologies and professional practice in dementia care

- 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

- 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](http://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.”