Healthy Ageing: the Grand Challenge

Manchester, 19 March 2019

Living Well with Dementia?!

Fears, realities and inspirations

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NHS Sussex Partnership NHS Foundation Trust

ydn Young Dementia Network

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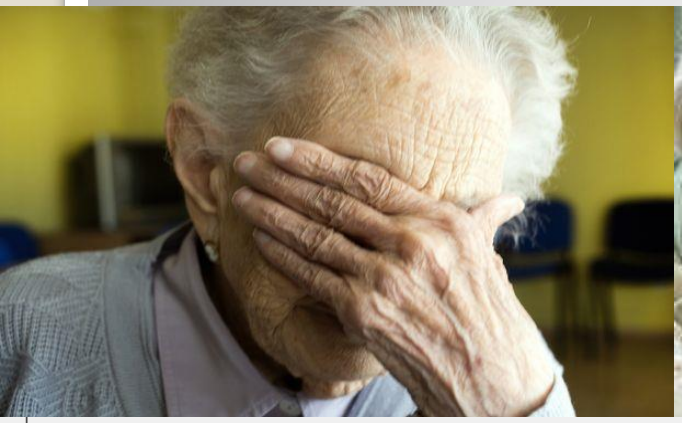
Fear 1: the stigma of 100 years



Dementia is our most-feared illness, more than heart disease or cancer.

David Perlmutter

Fear 2: the prevalence lottery

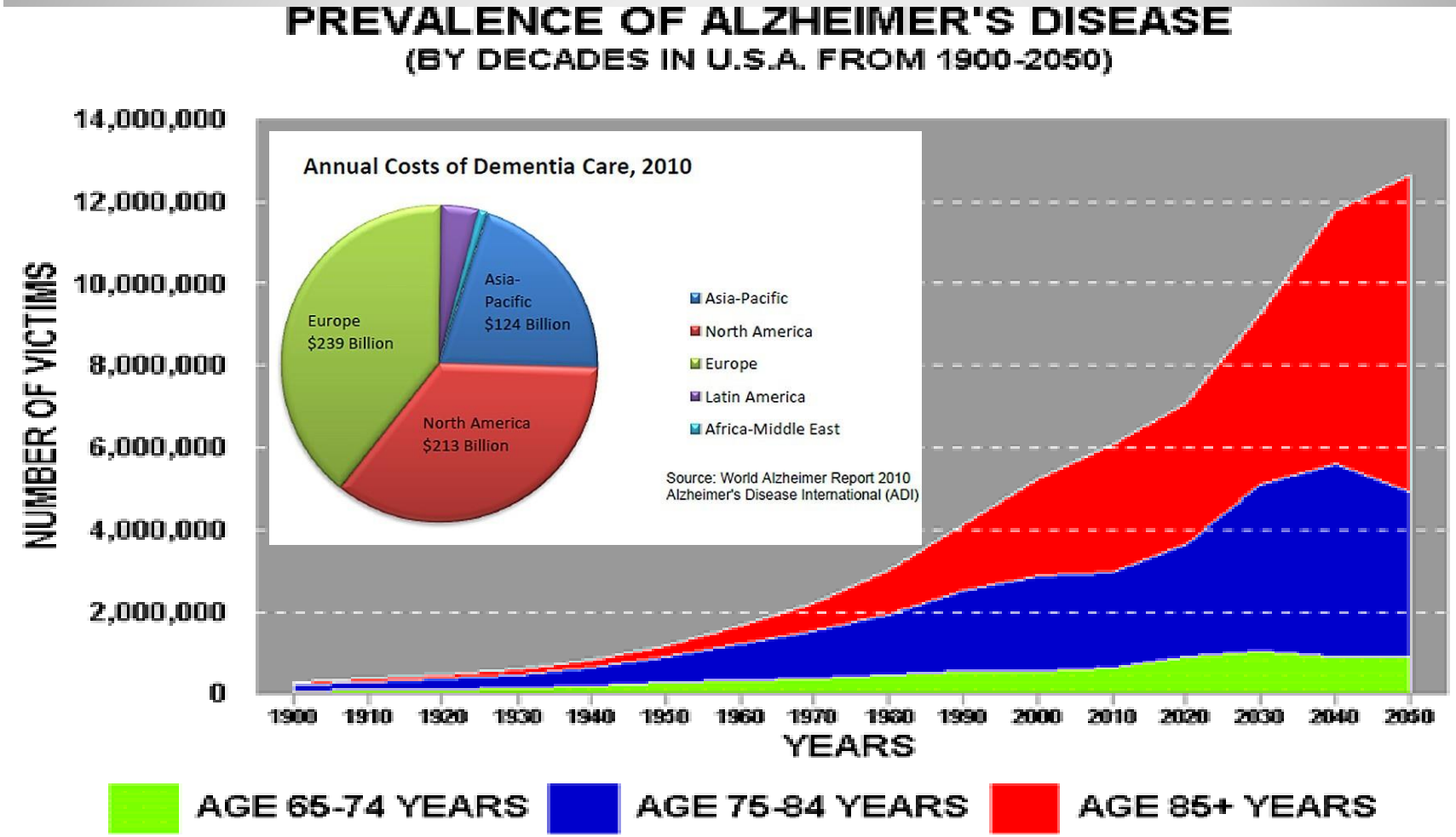
40–64 years
1 in 1,400

65–69 years
1 in 100

70–79 years
1 in 25

80+ years
1 in 6

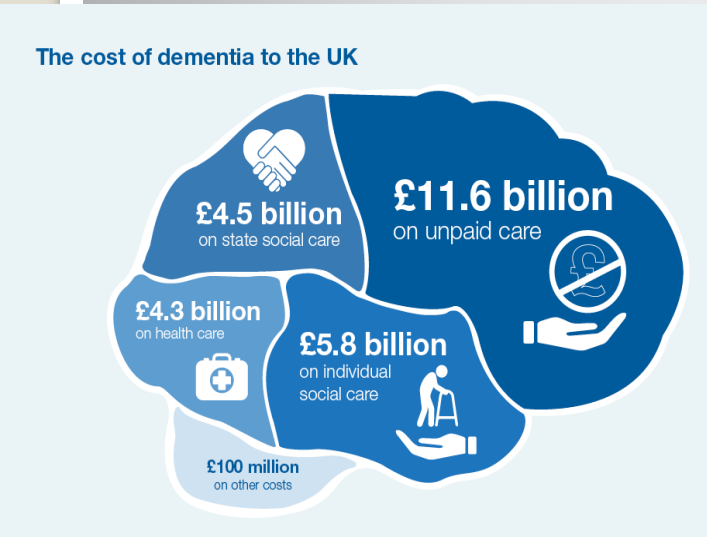
Fear 3: an economic and policy nightmare for govenments

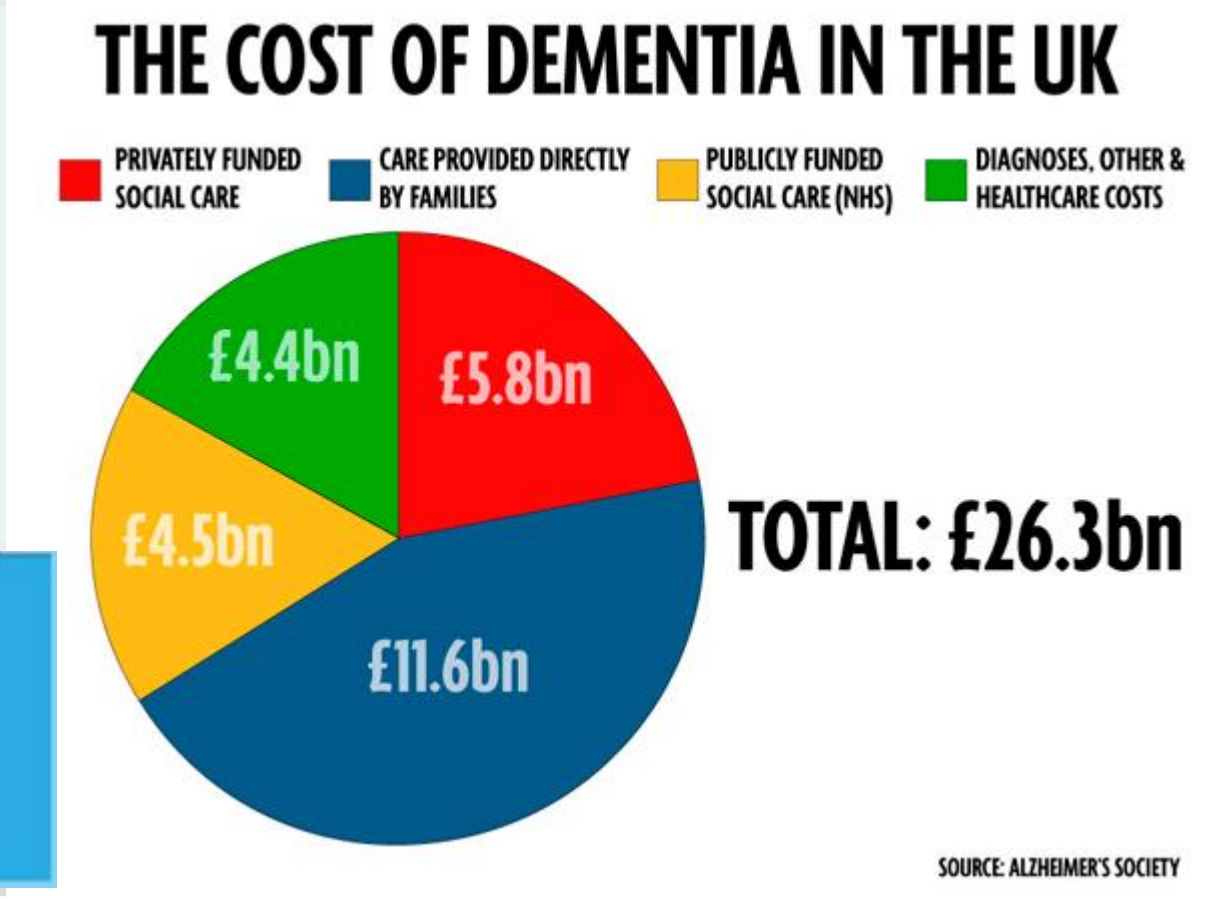


This graph portrays how many Americans over the age of 65 are currently affected by Alzheimer's, and a projection of how many more will become affected with it as time passes.

w3.ouhsc.edu

Fear 4: an economic nightmare for families and single people

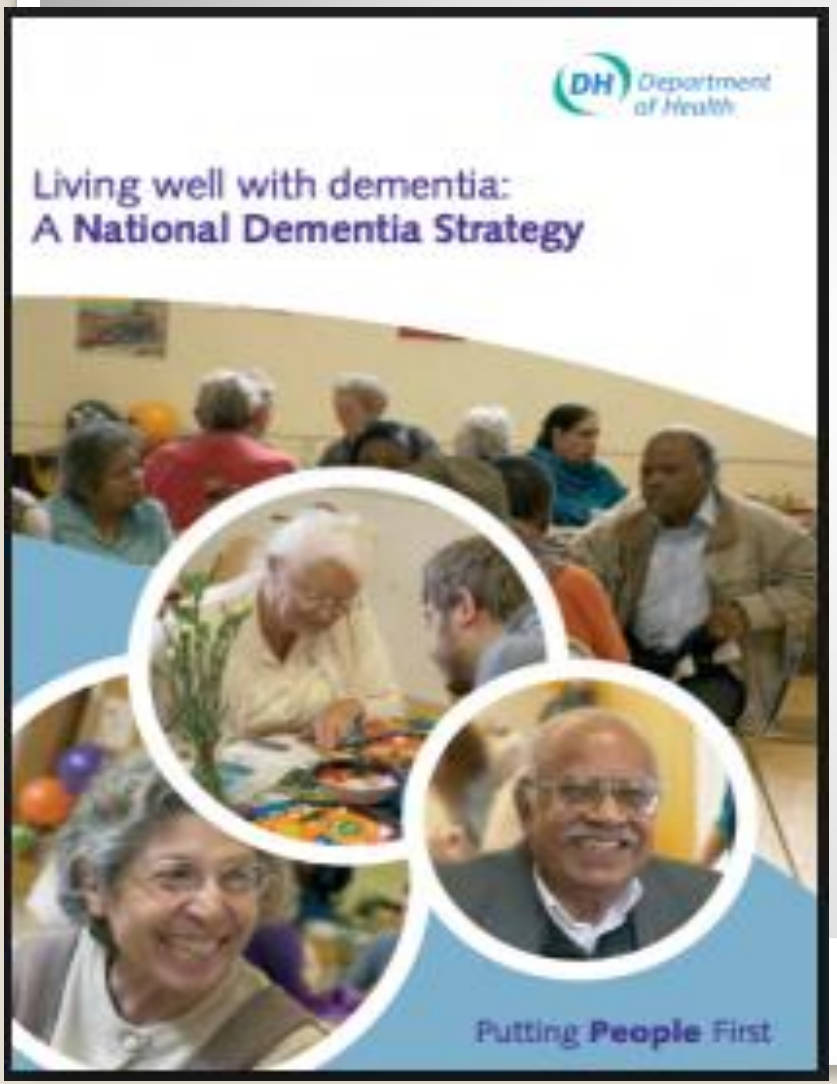




Fears 5 upward

- The loss of intellect when mental sharpness is valued
- Dependency on help, support, care where independence is valued
- Being a burden to others
- The imagery of the vegetables
- A loss of the very essence of the self
- The legacy of the backwards in hospitals
- The history of the poor house
- … … …

2009: A new Hope



- Early diagnosis
- Reducing stigma
- Staff training
- Research
- Support & services

The best country in the world to live with dementia

Implementation?

- **Austerity**
- **NHS Reforms**
- **Social Care Crisis**
- **Postcode lottery**

Living Well With Dementia: a national dementia strategy - good practice compendium

13 January 2011, Guidance, DHSC

This good practice compendium has been brought together from across the regions to support local delivery of the national **dementia** strategy and improve outcomes for people with **dementia** and their carers.

Challenge on dementia 2020: implementation plan

6 March 2016, Guidance, DHSC

Details how the Prime Minister's challenge on **dementia** 2020 will be met.

Department of Health & Social Care

Department of Health & Social Care

Dementia: applying All Our Health

23 January 2018, Guidance, PHE

Evidence and guidance to help healthcare professionals maximise their contribution to supporting the health, wellbeing and independence of people with **dementia**.

After a diagnosis of dementia: what to expect from health and care services

17 May 2018, Guidance, DHSC

A guide to the support people should get from local services in England if they or someone they know have been diagnosed with **dementia**.

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RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

Memory Services National Accreditation Programme (MSNAP)

Standards for Memory Services

Editors: *Sophie Hodge, Emma Hailey, Amy Colwill, Leanne Walker, Martin Orrell*

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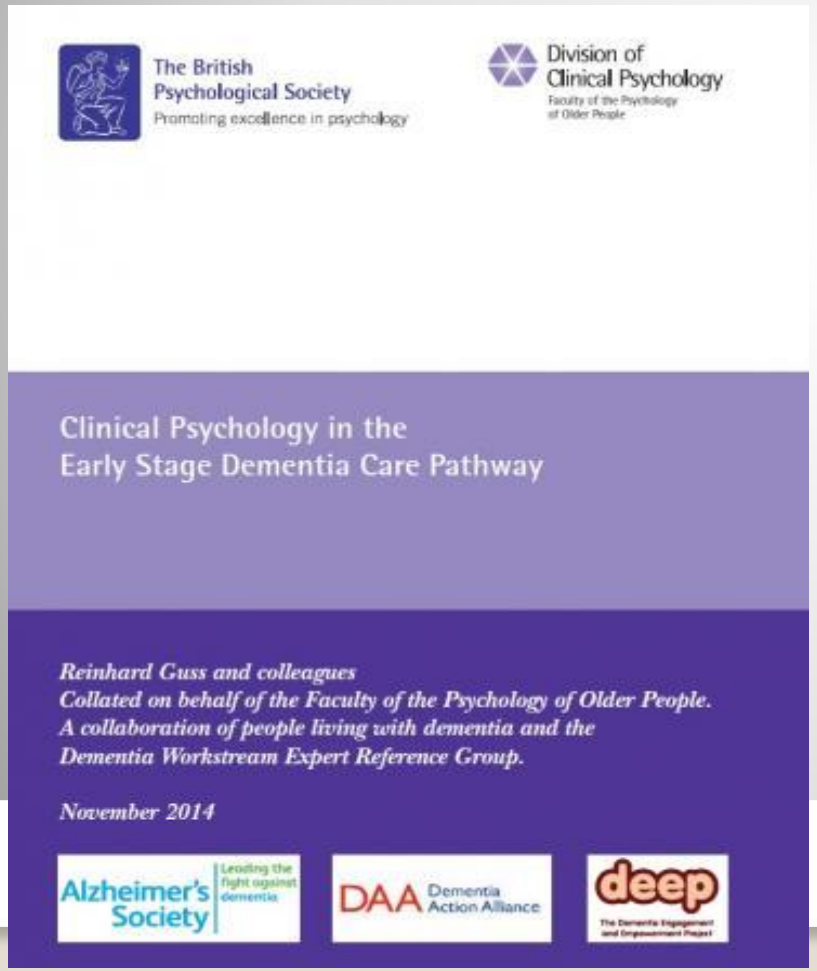
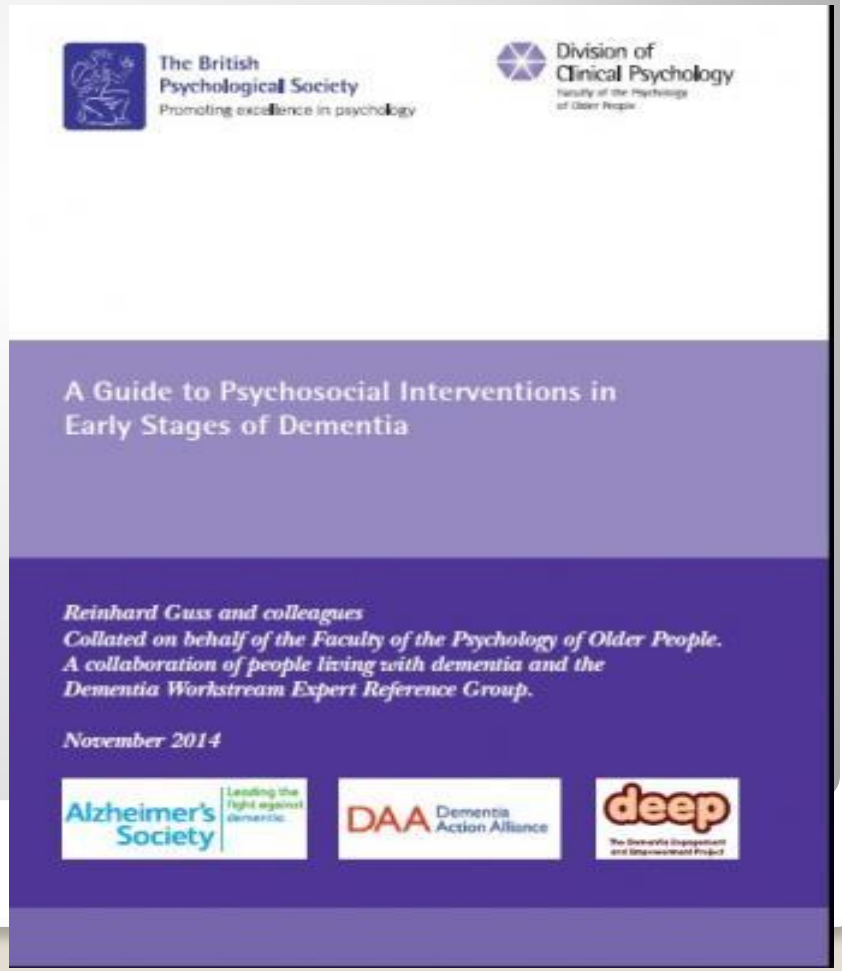
FPOP early dementia papers:

www.bps.org.uk/fpop

free to download + Accessible version 2016





Factors affecting "living well"- IDEAL study:

main factors are psychological

Excess Disability

- In healthy people anxiety and depression affect cognitive functioning:
  - Executive functioning: processing speed and capacity, "tunnel vision", judgement, reasoning, attention, planning
  - New learning, delayed memory
  - Visual/spatial processing and perception
  - Language, word finding, expression, fluency
- A compromised brain is more vulnerable, the effects of anxiety /depression are heightened and more disabling
- Reducing excess disability can be highly effective in improving quality of life and functioning.

Psychological treatments and psychosocial interventions

- No new drugs in 20 years, but development in psychosocial treatments
- Making best use of cognitive reserves and building cognitive resilience
  - Cognitive rehabilitation
  - Cognitive and environmental strategies
  - GREAT trial results
- Increasing emotional resilience
  - Psychological therapies adapted for working with people with dementia

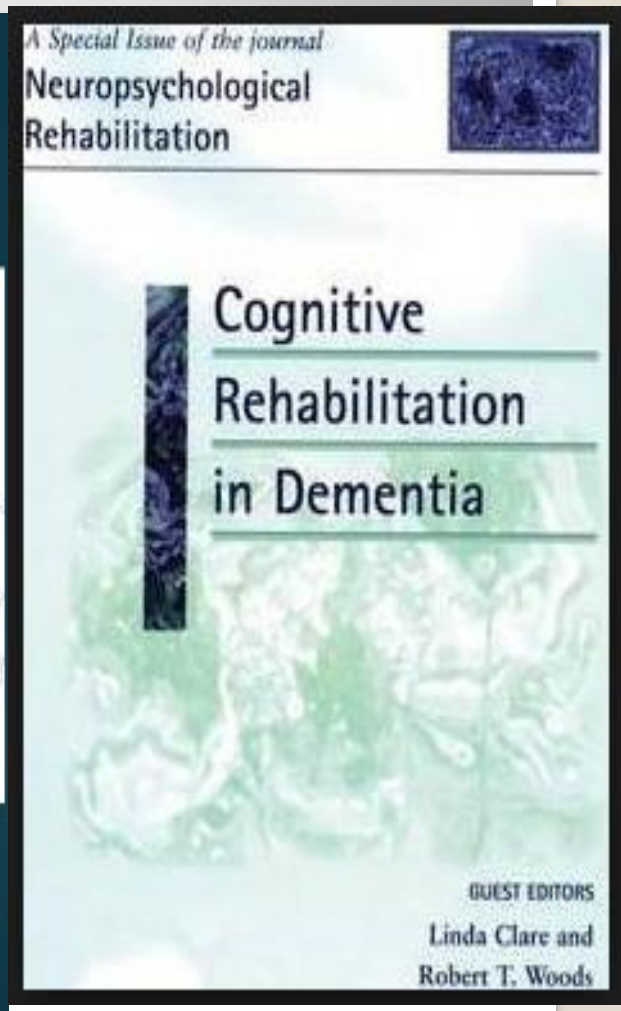
Cognitive Rehabilitation

Goal-oriented Cognitive Rehabilitation in Early-Stage Alzheimer's Disease and Related Dementias: Multi-centre, Single-blind Randomised Controlled Trial

GREAT

- **Aim:** To determine whether goal-oriented cognitive rehabilitation is a clinically-effective and cost-effective intervention for people with early-stage dementia and their family carers.
- **Chief Investigator:** Professor Linda Clare
- **Funder:** UK NIHR, Health Technology Assessment Programme
- **Participants:** People diagnosed with Alzheimer's disease (AD), vascular dementia, or mixed AD and vascular dementia (with a carer); MMSE score of 18 or above (or equivalent)

NHS
National Institute for Health Research



BPS Dementia Guidance

download free from:
www.bps.org.uk

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Cognitive disability & psychol. therapy: lessons from Neuropsychology, Acquired Brain Injury and Intellectual Disability

- **Therapy works!**
  - **Reductions in distress, increase in functioning, improvement in excess disability**
- **Therapy works better with experienced therapists**
  - **Understand nature of cognitive disabilities**
  - **familiarity with the client group**
  - **knowledge about the nature, specific issues and interactions of cognitive difficulties, causes and wider societal and relational effects**

Resilience

throughout Dementia

- Cognitive resilience, coping strategies
- Emotional resilience
  - Resilience as Thriving
  - Resilience as regulation of emotion.
  - Resilience as the norm.
  - Resilience as adult developmental opportunity.

"Reserve"
the mind's resistence to damage to the brain

Brain reserve – the hardware
- Size matters
- Number of connections
- A threshold model

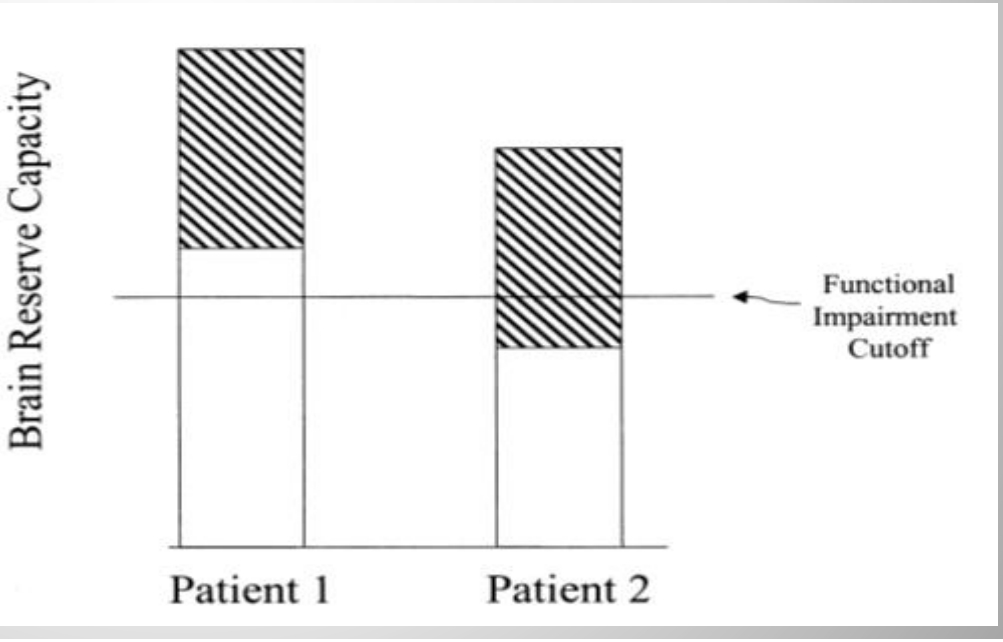
- **Cognitive reserve – the software**
  - Education & Occupation
  - Lifestyle
- **Global reserve – an interaction**

"Reserve"
the mind's resistence to damage to the brain

The mind's resilience evaluated behaviourally, neuropathological damage histologically, blood-based markers and imaging

The difficulty of assumed cut-off points/thresholds

The concept of "functional impairment"



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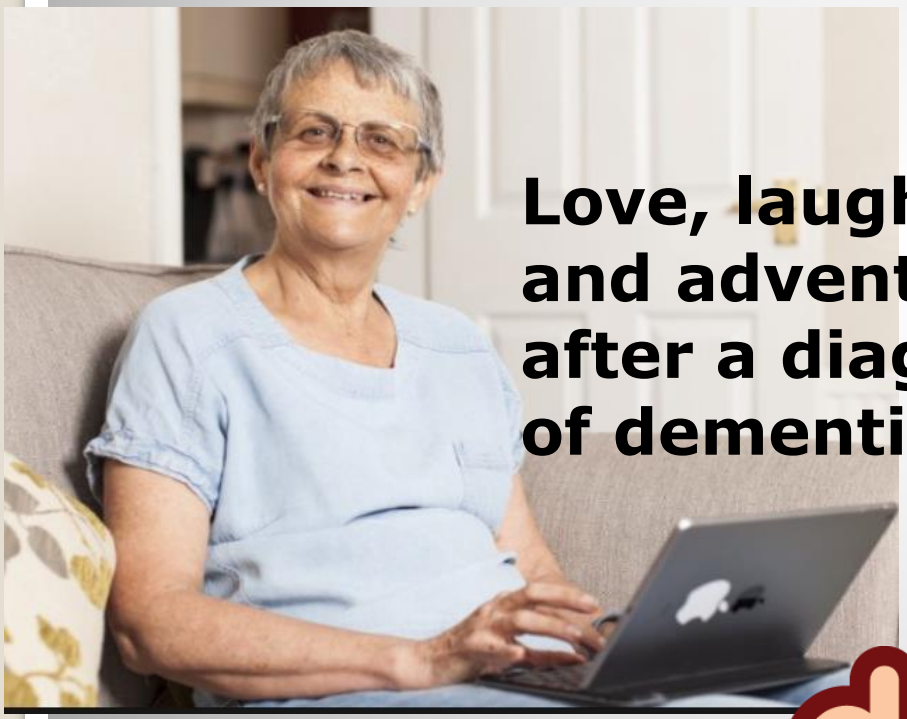
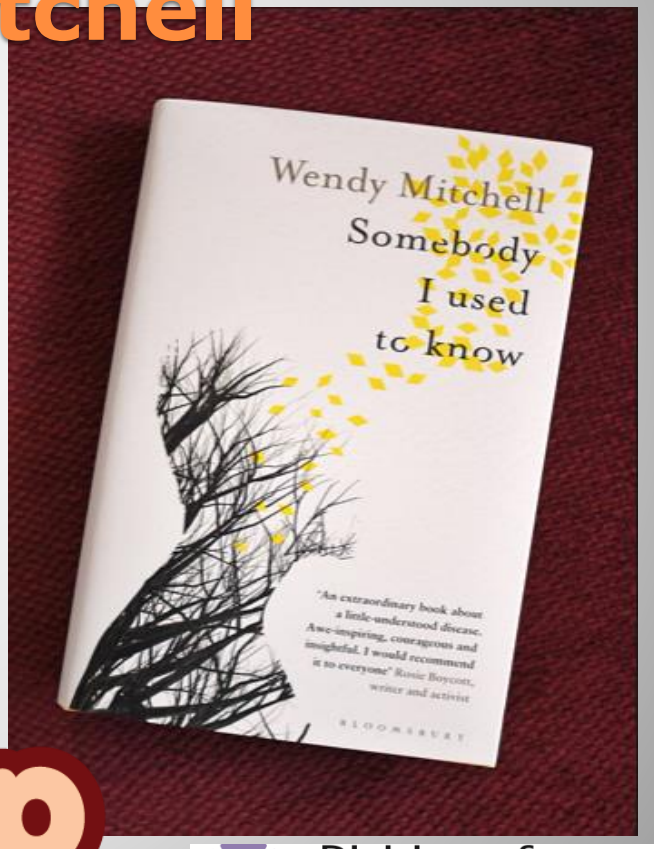
Learning from the Dementia involvement and empowerment movement: Wendy Mitchell



Love, laughter and adventure after a diagnosis of dementia



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Example: Dementia Diaries

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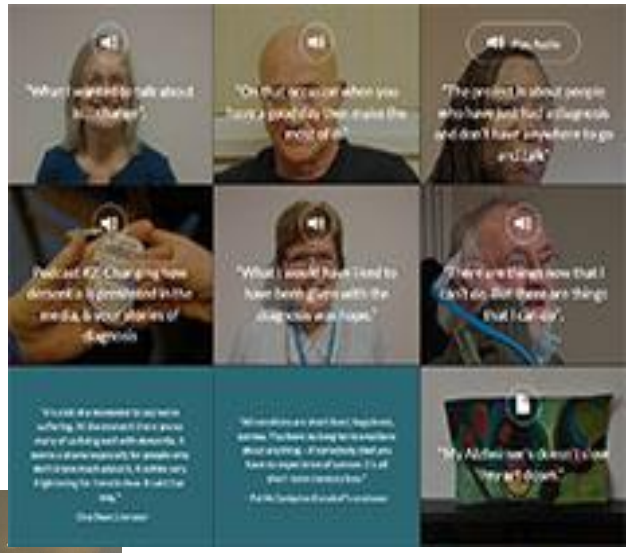
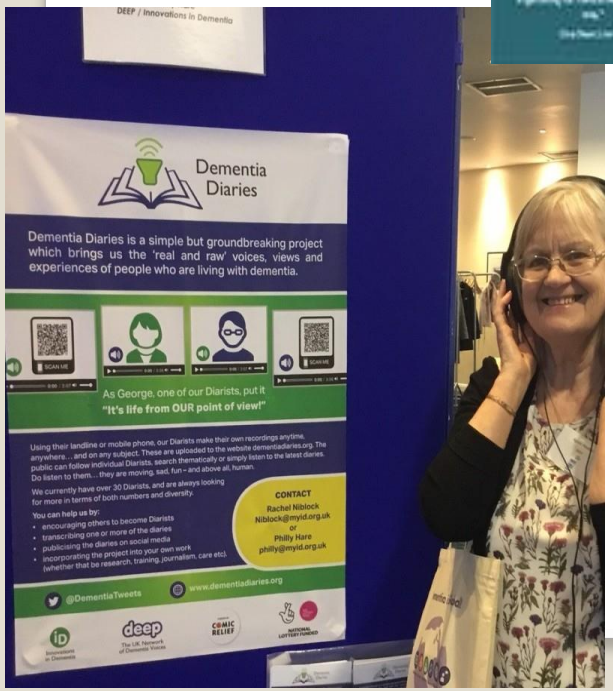
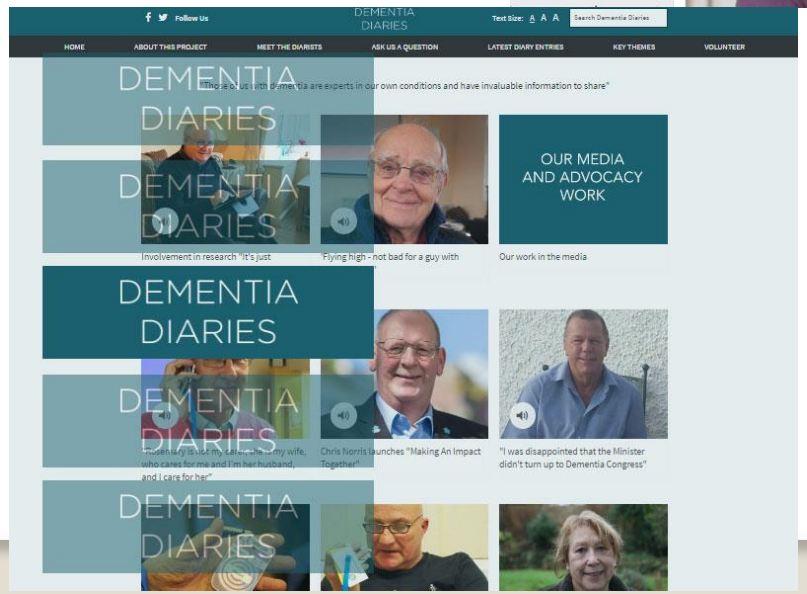


ON OUR RADAR
DEMENTIA DIARIES



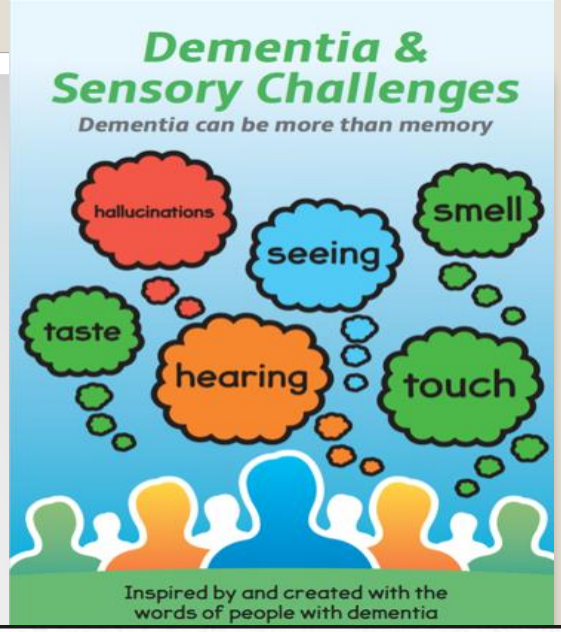


Dementia Diaries

Agnes Houston

Agnes Houston, Chair, Scottish Dementia Working Group

JRF | JRHT



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Example: DEEP Dementia Engagement and Empowerment Project

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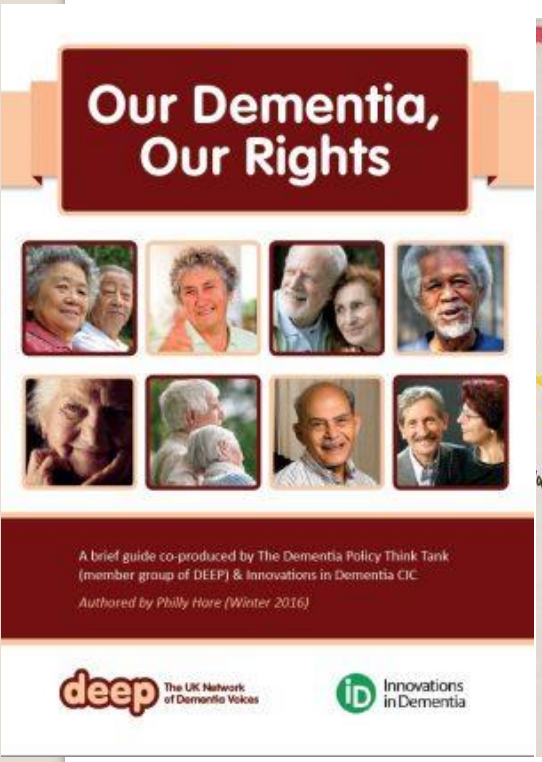
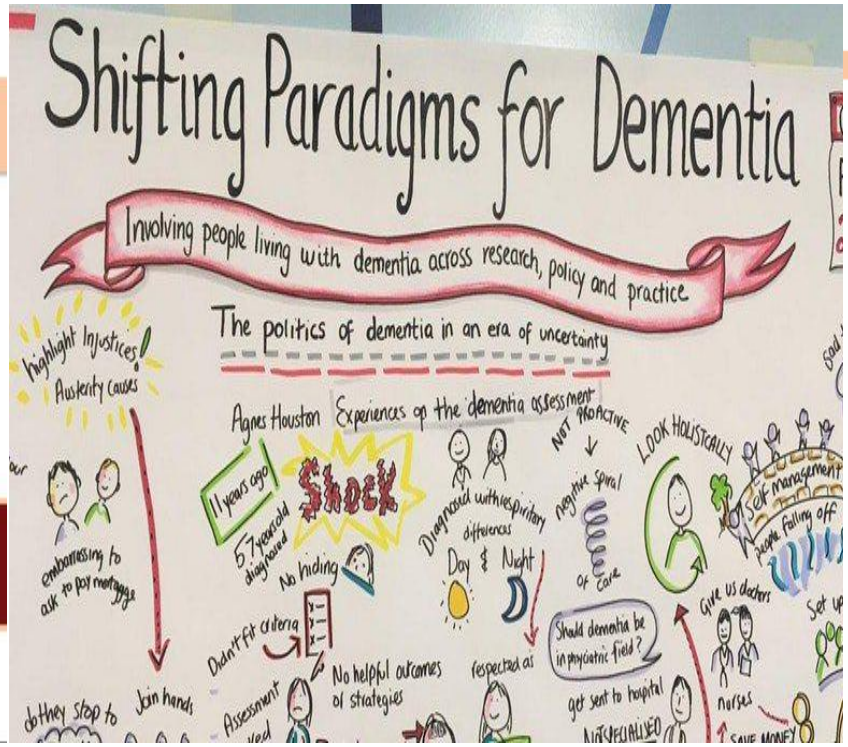
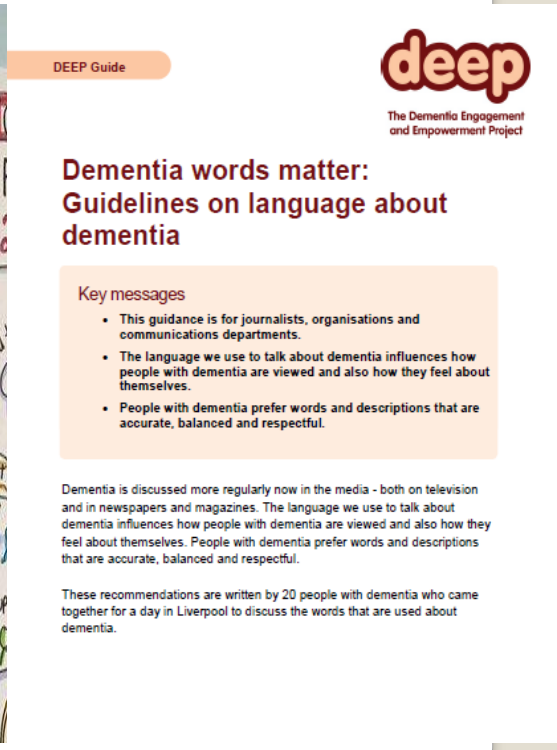
iD Innovations in Dementia






DEEP Guide

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Dementia words matter: Guidelines on language about dementia

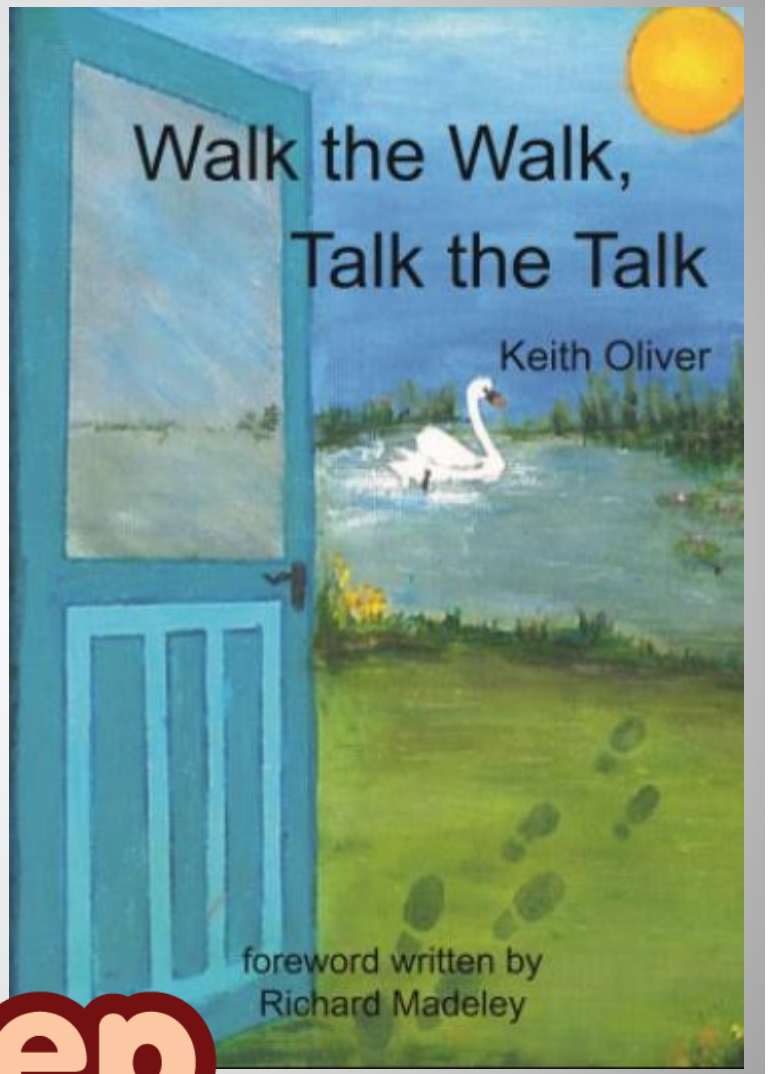
Key messages

- This guidance is for journalists, organisations and communications departments.
- The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves.
- People with dementia prefer words and descriptions that are accurate, balanced and respectful.

Dementia is discussed more regularly now in the media - both on television and in newspapers and magazines. The language we use to talk about dementia influences how people with dementia are viewed and also how they feel about themselves. People with dementia prefer words and descriptions that are accurate, balanced and respectful.

These recommendations are written by 20 people with dementia who came together for a day in Liverpool to discuss the words that are used about dementia.

Keith Oliver



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3NDG

3 Nations Dementia Working Group

Chris Roberts & Jayne Goodrick

Panorama documentary
European Dementia Working Group
Twitter, Facebook, Zoom…

- **Care partner**
- **Camper van**

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In conclusion:
A good quality of life is possible and increasingly common despite dementia

- Early diagnosis
- Retaining control
- Support for adjustment
- Active and engaged
- Disability rights, human rights
- "dementia friendly" city, church, business, society

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Thank you!

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