Parents & carers network

Understanding dementia

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A bit about me...

- Researcher/lecturer, not healthcare practitioner
- Conducted research with people with dementia and family carers (in-depth interviews, questionnaires)
- Research on evaluating mental health services (treatment effectiveness)
- Teach about dementia and other mental illnesses & ageing to MSc Gerontology students
- More recently research on ethnicity and care in later life
- Supervising PhD students on dementia

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Outline of session

- Background information
  - *how common is dementia?*
  - *what exactly is dementia?*
- Treatment and support available
- Where to get help
- Difference between dementia and normal ageing
- New developments at UoS

Questions welcome throughout

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Question

- Is anyone here caring for someone with dementia?
- Is there anyone who thinks this might be the case in the future?

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Prevalence - UK

- In **2007** there were estimated to be **683,597** people in the UK who had dementia (Knapp & Prince, 2007)

- ***Due to the ageing population*** =>
  - By **2051** there are expected to be over **2 million** people in the UK with dementia (Prince *et al.*, 2014)

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Prevalence of dementia slowing over time?

- Multi-centre longitudinal study of cognitive ageing in England & Wales (MRC CFAS)
- In 1994 they estimated that there would be **884,000** people aged 65+ with dementia by 2011
- *However*, the later data allowed an estimate of **670,000** people aged 65+ with dementia in 2011
- A cohort effect – the numbers of people with dementia are not increasing as quickly as was once predicted
  - *Potentially due to healthier lifestyles, better education, improvements in care, etc.*

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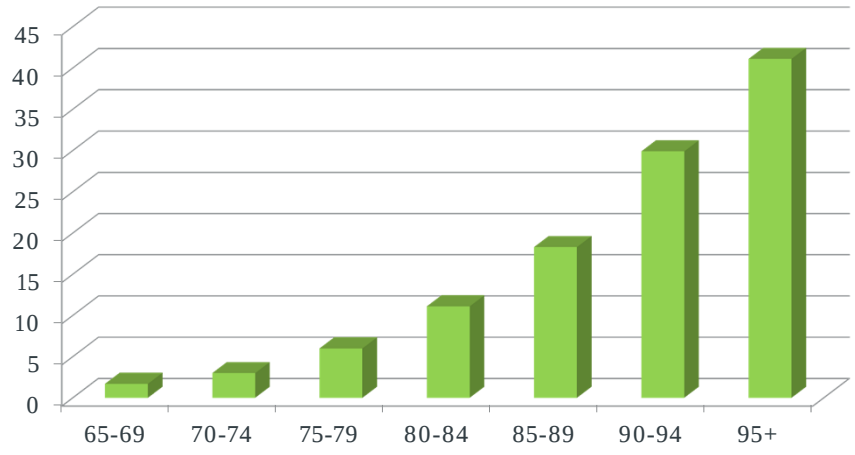
(Matthews *et al.*, 2013)

Figure 1: Prevalence of dementia rises with age (UK)



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Source: Prince *et al.* (2014)

Definition

- Dementia is a **syndrome** caused by a **disease** of the brain
- There are **several different types** of **disease** that can cause dementia
- Dementia is **not** a **normal** part of ageing
- Dementia affects more than just **memory**
- People **under the age of 65** can develop dementia
- Dementia is currently **incurable** (but lots can be done to help people *live well* with dementia)

International Statistical Classification of Diseases and Related Health Problems, 10th revision (2007)
http://apps.who.int/classifications/apps/icd/icd10online/

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Most common form of dementia

- Alzheimer's disease
  - Usually an 'insidious' onset, with a gradual decline of cognitive functions. Decline may increase in speed toward the later stages. Stages of mild, moderate and severe usually identifiable.
  - Duration of disease depends on the timing of diagnosis (mean ranges from 1 - 16 years; median 5 - 6 years)
  - Entire disease process could be 20+ years

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Figure 2: Other types of dementia

N.B. This is not an exhaustive list of all types of dementia
See also Chapter V http://apps.who.int/classifications/apps/icd/icd10online/

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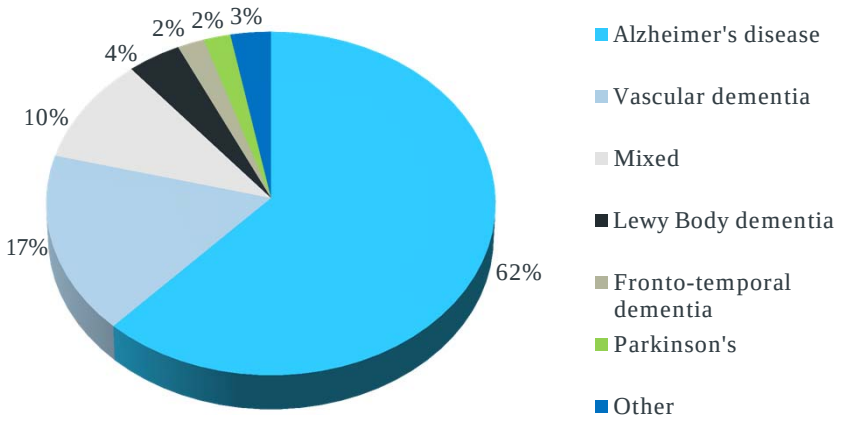
Figure 3: Distribution of dementia subtypes (UK)



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Source: Knapp &Prince (2007)

Question

- What sorts of symptoms and behaviours would you associate with dementia?

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Behavioural and psychological symptoms of dementia (BPSD)

- As well as cognitive problems, people with dementia also have a range of behavioural and psychological symptoms
- These symptoms are often the most distressing for family members, and contribute to 'carer burden' more than cognitive impairment
- They include: delusions, hallucinations, depression, anxiety, agitation, aggression, 'wandering', sleep problems, eating problems
- People with dementia may also experience incontinence
- These symptoms are present to different extents depending on the type of dementia, and across individuals.

(Thomas, 2008)

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Low diagnosis rates

- **It is relatively difficult to diagnose Alzheimer's disease:**
  - There is no simple blood test or brain scan that definitively diagnoses AD
  - We cannot examine the brain fully until after death
  - We have to exclude alternative possible causes for cognitive impairment / behavioural changes
- **Dementia is often not recognised as a disease:**
  - In the early stages memory impairment is often assumed to be 'normal' ageing (by patients and doctors)
  - In some cultures there is no word for 'dementia', and it is not recognised as a disease

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Importance of early diagnosis

- "Diagnosis is the gateway for care" (Knapp & Prince, 2007: 47)
- **Treatment can begin as early as possible** - some drug treatments can maintain the person with dementia at their current stage for a limited period of time
- **Planning** - plans for future care decisions can be made while the person with dementia is capable of making these decisions
- **Reducing anxiety** - once a diagnosis has been made the future can be anticipated and prepared for, less fear of the unknown

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Experiences of receiving a diagnosis

"It helps everybody, anybody who's involved, to understand the problem or ways round it. At the same time, it also points out to you...that, you know, there is no magic cure." (person with dementia)

"I think...confirming the...diagnosis...is the first thing, because 'till you know what you're treating then, you know, you're shooting in the dark." (carer)

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(Willis *et al.*, 2009)

What treatment/support is available?

- Biomedical approaches
  - Drug treatments
- Psychosocial approaches, e.g.
  - Support groups
  - Reminiscence therapy
  - Cognitive stimulation therapy
  - Etc...
- Personal care (informal sources, paid care, care homes, etc)
- Plus much more...(e.g. voluntary sector)

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(Innes, 2009; Woods & Clare, 2008)

Drug treatments

- Acetyl Cholinesterase Inhibitors (AChEIs)
  - *Rivastigmine, Galantamine, Donepezil*
  - Can improve cognitive function and ADLs in *Alzheimer's* disease *(also for Mixed Dementia)*
  - Cost effective for mild to moderate Alzheimer's disease
- *Memantine*
  - Can improve cognitive function, ADLs and neuropsychiatric symptoms
  - For severe Alzheimer's disease, and in some cases for the moderate stage

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(Telford *et al.*, 2012)

Importance of informal carers

- In the UK, about two thirds of people with dementia live in their own home, supported by family members or friends
- The majority of day-to-day care is provided by family members or friends
- Additional support can be provided by professional staff, e.g. care workers visiting the person with dementia at home to help them get washed or dressed
- People who live in care homes are supported by the care home staff, and also by their family members who visit, some continuing to provide personal care or provide food inside the care home

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(Knapp & Prince, 2007)

Support services for carers

- **Respite** (within own home, few hours or overnight, in a care home)
- **Peer group support** (carers groups)
- **Dementia cafes** (for both carer and person with dementia)
- **Voluntary sector** organisations, e.g. **Carers UK** http://www.carersuk.org/

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Where to get help?

- **Alzheimer's Society** www.alzheimers.org.uk
  National Dementia Helpline: 0300 222 1122
- **Age UK Southampton** www.ageuk.org.uk/southampton
  023 8036 8636
- **Ask your GP** for a memory assessment and/or a referral to a memory clinic or community mental health team
- **Carers in Southampton**
  www.carersinsouthampton.co.uk 023 8058 2387
- **Southampton social services**
  adult.contact.team@southampton.gov.uk 023 8083 3003
- Considering a care home? Look at **Care Quality Commission** ratings www.cqc.org.uk

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Question

- Who is concerned about their own memory?
- What sort of memory changes do you think might happen to everyone (normal ageing)?

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Distinction between 'normal' and 'pathological' changes with age

- Some deterioration in cognitive functioning is common to the majority of older people, without significantly affecting daily life
- In others, deterioration in cognitive functioning is more severe, and is indicative of an underlying illness, e.g. dementia
- But what is 'normal'?

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Examples of difference between normal age related changes in cognition and dementia

Normal ageing	***Possible signs of dementia***
• Occasionally forgetting where you left your keys	• Forgetting what keys are for
• Needing a few minutes to recall where you parked your car	• Forgetting how to drive
• Word finding difficulties (tip-of-the-tongue)	• Misusing words, difficulty following a conversation
• Same judgement as always	• Loss of judgement

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Normal brain changes with age

- Physical changes in the brain; shrinkage (atrophy), slower transmissions, fewer synapses (Stuart-Hamilton, 2012).
- Brain volume (mass) decreases over a lifetime (up to 10-15%), particularly in the frontal lobes (Rabbitt, 2005).
- The result of this is an overall reduction in efficiency of brain functioning.
- Importance of the frontal lobes for cognitive function, e.g. attention, planning, reasoning, sequencing of actions.

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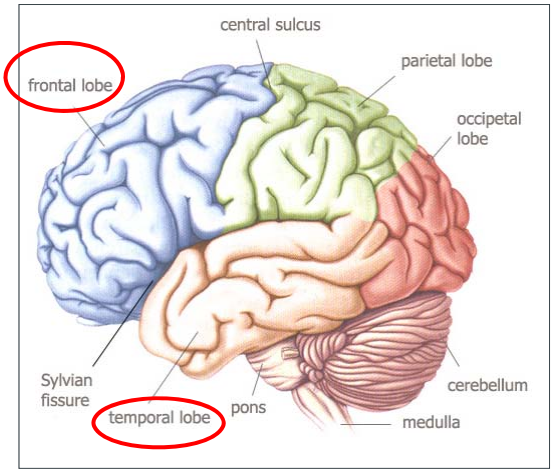
Figure 4: Parts of the cerebral cortex controlling memory



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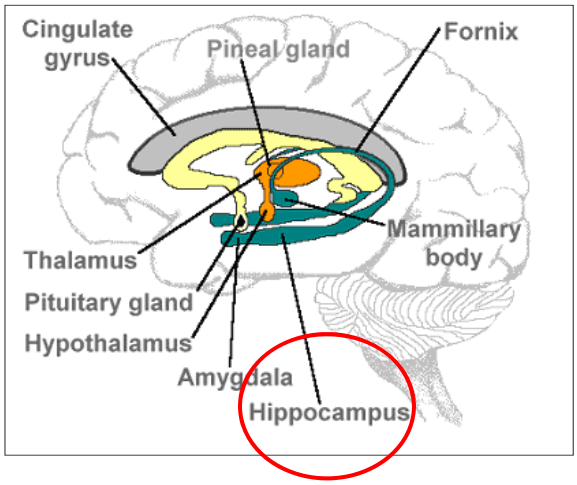
http://neuro.sofiatopia.org/ibrain4.jpg

Figure 5: Parts of the forebrain controlling memory



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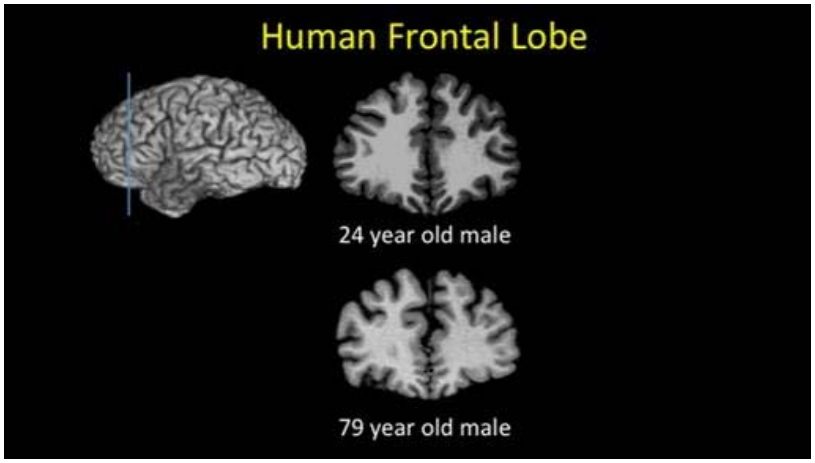
http://thebrainlabs.com/Images/hippocampus.gif

Figure 6: Normal shrinkage of the brain with age



Source: Sherwood et al (2011)

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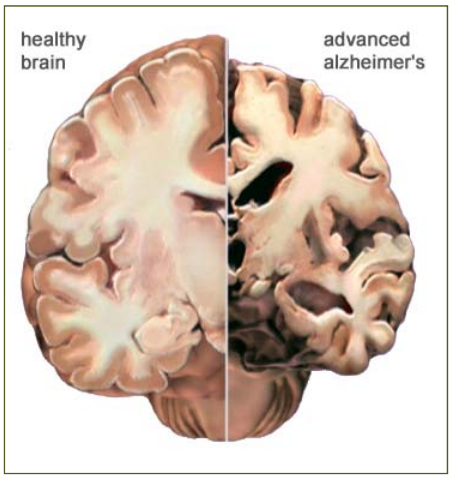
Figure 7: Brain changes in Alzheimer's disease - atrophy



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Source: http://www.alz.org/braintour/healthy_vs_alzheimers.asp

Normal changes in memory with age

- **Short term** memory (working memory)
  - simple tasks (older people slightly worse)
  - complex tasks (older people quite a lot worse)
- **Long term** memory (older people worse than younger)
- **Semantic** memory (older people as good or better)
- **Destination** memory (older people worse)
- **Prospective** memory (older people as good or better)

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(Stuart-Hamilton, 2012)

Implications of studies of cognition and ageing

- **Reaction times** - if we statistically control for reaction time the difference between the age groups in many laboratory cognitive tests is eliminated
- **Individual differences** - the findings relate to the mean of older people compared to the mean of younger people
- **External invalidity** –does it matter if people perform poorly in a laboratory experiment, if they are still able to perform the task in 'real world' settings?

(Rabbit, 2005; Stuart-Hamilton, 2012)

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What can be done about cognitive decline?

- **Physical exercise:** aerobic exercise has been shown to improve scores on working memory, spatial ability, and speed of processing (Colcombe & Kramer, 2003)

- **Computerised cognitive exercise:** it seems to work, but it has limited transferability (Verhaegen, 2011). Some findings indicate that group based training is more effective than solo training (Lampit *et al.*, 2014).

Photos: Google Images. Other brain training software is available!

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What's happening at Southampton?

- In 2015, the Alzheimer's Society funded eight Doctoral Training Centres in Dementia around the country
  - This is the single biggest funding commitment to support early-career dementia researchers in the UK (almost £5million)
- The University of Southampton was successful in its bid to win one of these centres
  - Bowling, Bartlett, Willis, Addington-Hall, Green, Bridges & Roberts
  - Faculty of Health Sciences, Faculty of Social & Human Sciences
- Southampton's Doctoral Training Centre in Dementia Care focuses on *Researching patient safety and risk enablement* in different care settings (own home, care home, hospital)
- *First PhD students start in September 2015!*

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Thank you

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