

Supporting families in dementia care: practice and research



DementiaUK

Helping families face dementia

Rachel Thompson

Consultant
Admiral Nurse,
Lewy body
dementia

www.dementiauk.org

356 Holloway road. London N7 6PA

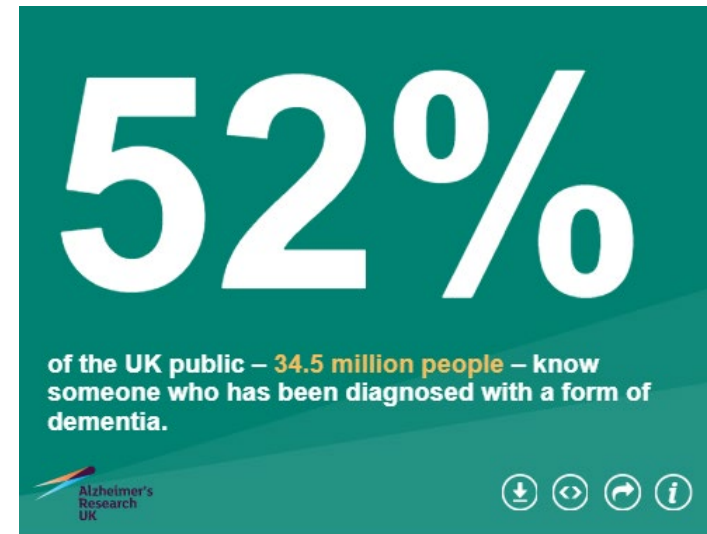
020 7697 4174

info@dementiauk.org

@DementiaUK

Registered Charity Number 1039404

Dementia - 'everyone's business'



850,000 people in the UK with dementia
42,000 people under 65

Anticipated increase = 2 million by 2050

63.5% in community
36.5% in care homes (approx. 69% with dementia)
25% of people in hospital

Dementia; the hidden voice of loneliness (Alzheimer's Society, 2013)
Dementia UK - Second Edition (Prince et al, 2014)

Main types of dementia

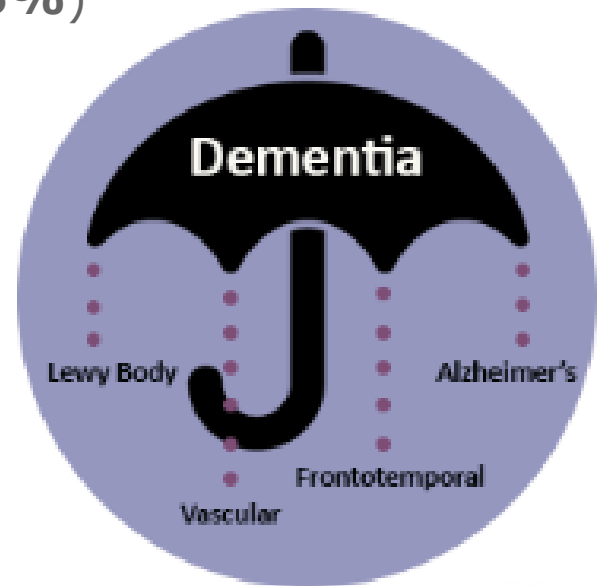
- Alzheimer's disease (approx. **60%**)
- Vascular dementia (approx. **20%**)
- Lewy body dementia (approx. **10-15%**)
- Mixed dementia (usually Alzheimer's disease and vascular)

Other types more likely to affect **younger people** (i.e. people under the age of 65) include:

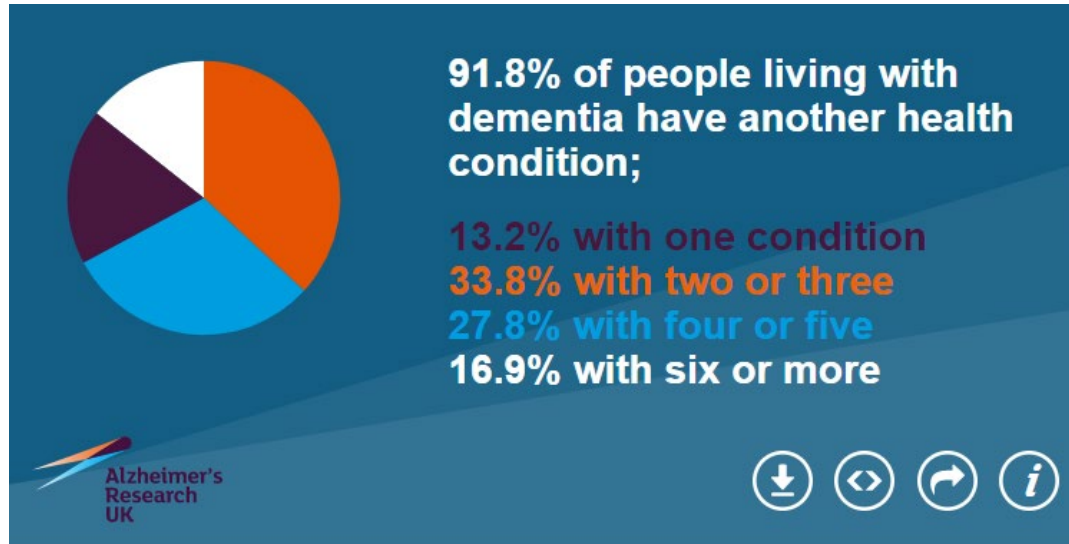
- Frontotemporal dementia (FTD) (approx. **5%**)
 - Behavioural variant (BvFTD)
 - Primary progressive aphasia (PPA)
- Posterior-cortical atrophy (PCA)

There are many other less common types e.g.

- Progressive Supranuclear Palsy (PSP)
- CADASIL
- Huntington's
- HIV
- Corticobasal syndrome
- Normal Pressure Hydrocephalus
- Niemann Type C



Co-morbidities and dementia



Common Co-morbidities:

53% Hypertension

34% Painful condition

24% Depression

21% Chronic heart disease

13% Diabetes.....

Arthritis, urinary tract infection, incontinence, visual/ hearing impairment, etc.

Browne J et al (2017) Association of comorbidity and health service usage among patients with dementia in the UK; a population-based study

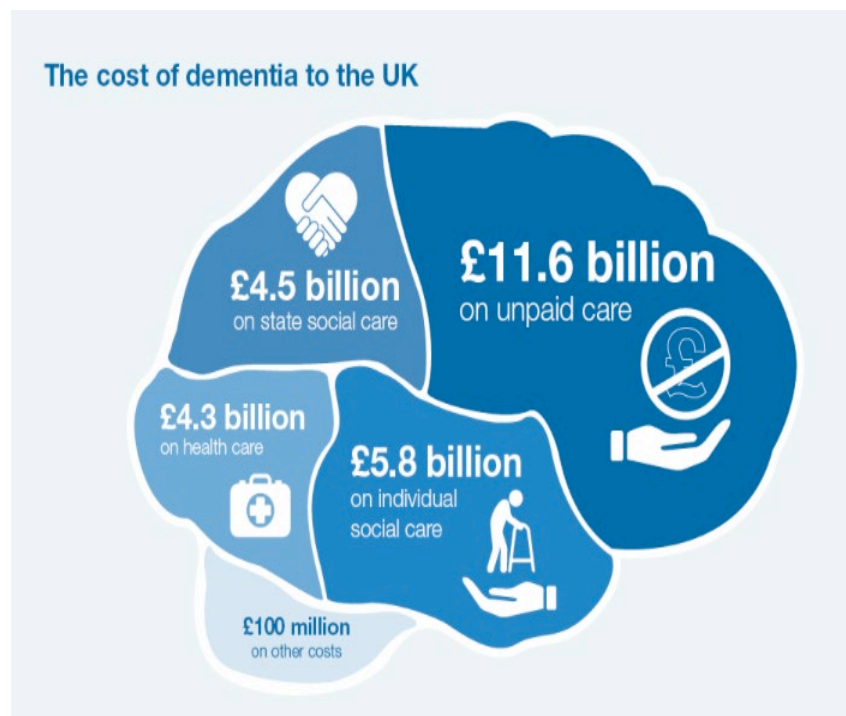
Policy & Research

Dementia 2020 Challenge Implementation Plan priorities

- Reducing risk
- Health and Care delivery
- Health & Care workforce
- Dementia awareness & social action
- Research

DHSC (2018) – ‘What to expect after a diagnosis of dementia’

- Care plan
- Named person – coordinator
- Help with day to day activities
- **Help for carers**
- Treatment
- Support with hospital
- Making decisions about future
- Research
- End of life care



NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p> <p>"I was given information about reducing my personal risk of getting dementia"</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p> <p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p> <p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	 <p>People with dementia can live normally in safe and accepting communities</p> <p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	 <p>People living with dementia die with dignity in the place of their choosing</p> <p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ , BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ , Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ , Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

**A diagnosis of dementia is not just given to one person
- it is given to a spouse, a partner, a child and the
extended family'**



Who are carers?

Carers are a diverse group

They include children and young people

Most carers provide support to a relative, usually a parent or spouse

Not all carers are related to the person they care for.

(BMA, 2009)



Definition of a carer?

Carers Act (1995)

A carer is an adult who provides or intends to provide a *substantial* amount of care on a *regular* basis

Care Act (2014)

Removes requirement to provide 'substantial care on a regular basis'. A carer is now defined as **"an adult who provides or intends to provide care for another adult"**

- Removes requirement to ask for an assessment.
 - Only requirement is that the carer 'may have needs for support – whether currently or in the future'.
- Carers will be given the same recognition, respect and parity of esteem with those they support.

Did you know...?

700,000

The **number of informal carers** for the 850,000 people living with dementia in the UK.



63% of carers for people with dementia are retired while 18% are in paid work. 15% of dementia carers say they are not in work because of their caring responsibilities.



36%

of carers spend more than **100 hours per week** caring for a person with dementia.



48.4%

of carers have a long-standing illness or disability.



How does it feel being a carer?

Ray's story:

<https://youtu.be/x8tzcvkd-FI>

Why support family carers?

Prevalence of depression among carers of people with dementia is estimated at between 40-60% (Cuijpers 2005; Chan et al 2013)

Being a caregiver for people with dementia is associated with both psychological stress and physical ill- health (Gilhooly et al 2006)

Behaviour disturbance and high level of neuropsychiatric disturbance is the most consistent predictor of carer burden
(Sink et al 2006, Gallagher et 2011, Chiao et al 2015)

Even at early stages of cognitive impairment, spouses may assume the role of family caregiver and experience both caregiver burden and psychiatric morbidity.



'The stresses or difficulties of caring are best understood from a subjective rather than an objective perspective, with the circumstances of care being less important than a carer's perception of them' (Nolan 2001)

How do family carers cope?



- Often do **not** see themselves as carers
- They cope as everyone else does
- Coping strategies mediate the relationship between 'burden' and coping
- Important to recognise 'motivation' and 'meaning' in caregiving

Types of coping strategies

1. Emotion focused
e.g. acceptance, emotional support, positive reframing,
2. Problem solving (traditionally what services offer)
e.g. active coping, getting practical support, planning/ new strategies,
3. Dysfunctional coping strategies
e.g. disengagement, denial, self-blame, substance use, venting

Supporting family carers

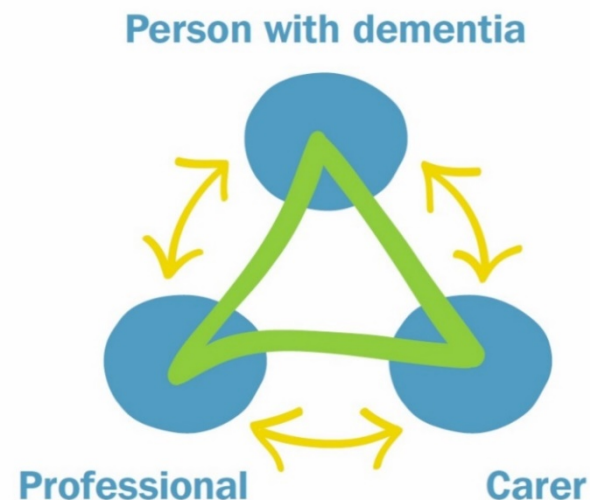
Approx **750,000** primary carers across UK.

Carers save economy approx **£13.9 billion** per year

Rates of depression and anxiety are high

Anticipatory grief & loss is a significant experience for families

Around 2/3rds of family carers of people with dementia experience loneliness



What helps families with dementia ?

- Psychoeducation -
 - understanding the condition and addressing emotional impact
- Skills training
 - responding to symptoms and developing positive coping strategies
- Respite & support tailored to individual needs
 - acknowledging differences/ individual preferences
- Emotional support
 - peer and professional
- Support from groups
 - peer and psychoeducation
- Intensive case management –
 - dedicated professional to coordinate care; individualised care plan

NICE Guidelines (2019) Dementia: assessment, management and support for people living with dementia and their family carers

What supports carers- the evidence?

Individualised, psycho-educational, skills-training programmes

e.g. REACH II (Belle et al 2006, Cheung et al 2014)

CBT based interventions: Focus on coping strategies: Emotion focused, problem solving & reducing dysfunctional strategies e.g. START (Livingston et al 2013)

Cognitive reframing - identify and modify negative beliefs and interpretations (Vernooij-Dassen et al 2011)

Family/ couple work – focus on relationships and preferences/ values e.g. SHARE (Witlach 2014)

Psychoeducation and peer support groups - Professionally-led support groups for caregivers of people with dementia found to be “significantly effective” (Chien, Chu, Guo, Liao et al., 2011)

What can you do to make a difference to family carers?

- Be curious – ask questions!
- Remember family carers often have information that may be crucial
- Recognise carers have their own needs/ Carers assessment
- Involve in assessment, care and planning
- Offer separate & inclusive conversations wherever possible
- Acknowledge the emotional impact of caring and possible anticipatory grief/ loss
- Highlight information and support i.e. understanding, coping strategies & practical/ emotional support



Admiral Nursing

Registered nurses who have specialist knowledge of dementia care

Provide support to family carers and people living with dementia, particularly when things are complex or difficult

Provide education, leadership, development and support to other colleagues and service providers

Offer holistic assessment, family & relationship centred approach and psychosocial support

Information and support for carers

Dementia UK <https://www.dementiauk.org/>

tide - together in dementia everyday <https://www.tide.uk.net/>

Carers UK <https://www.carersuk.org/>

Carers Trust <https://carers.org/>

Free on-line courses:

<https://www.futurelearn.com/courses/collections/dementia>

Rare Dementia support: <https://www.raredementiasupport.org/>

Keeping up to date

Useful websites


PHE Fingertips Tool: (Demographics & Stats)
<https://fingertips.phe.org.uk/>


Dementia Evidence Toolkit: (Reviews of Interventions)
<https://toolkit.modem-dementia.org.uk/>


Dementia Research Platform: (Portal for Dementia Research)
<https://www.dementiasplatform.uk/>


Alzheimer's Research UK: (Information & resources)
<https://www.alzheimersresearchuk.org/>

Join Dementia Research: (Campaign to increase engagement)
<https://learn.joindementiaresearch.nihr.ac.uk>

Dementia Evidence Toolkit

Evidence Summaries

Evidence Database

Research Methods

Welcome to The Dementia Evidence Toolkit

The Dementia Evidence Toolkit is for commissioners, care providers, people working in health and social care and people with dementia and their families.

The toolkit has two resources:

- [A searchable database with information on over 1433 research studies on interventions for people living with dementia and their carers](#)
- [Summaries of the research findings for some of the main care and treatment interventions](#)

An intervention is something that aims to make a change and is tested through research. For example this might be giving a medical treatment or drug, providing a counselling or care service, improving a person's environment or giving people information and training.

Thank you for listening



Admiral Nurse Dementia Helpline: 0800 888 6678
helpline@dementiauk.org

rachel.thompson@dementiauk.org