



# **Health and social care for older people living with dementia in the England**

Joint World Conference on Social Work, Education and Social Development 2016

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# Summary

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- Older people and dementia in the England: current and future trends
- What does it mean to 'live well' with dementia: perspectives from older people living with dementia and carers
- Challenges and solutions: dementia services and support within the health and social care system in England





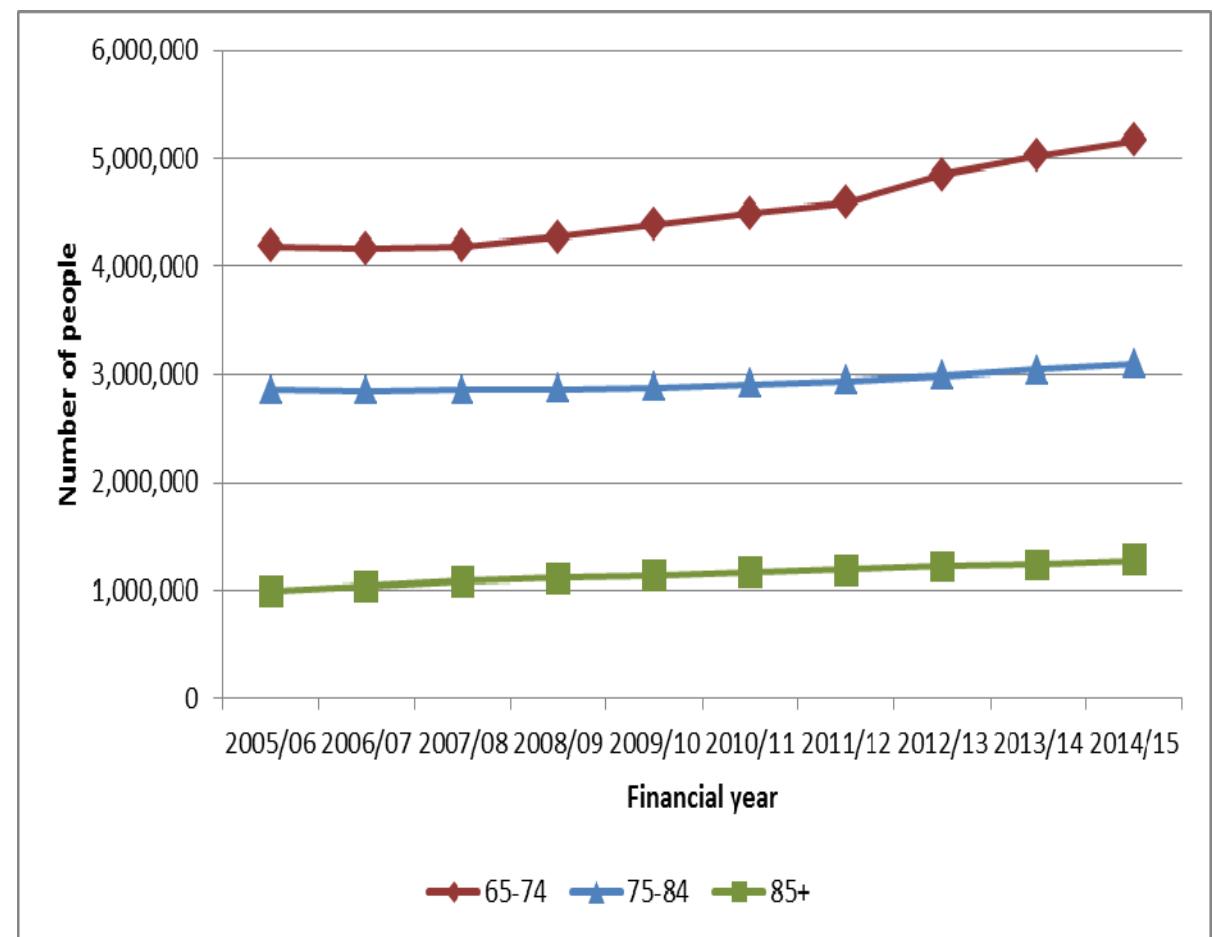
# Older people and dementia in the England

Current and future trends



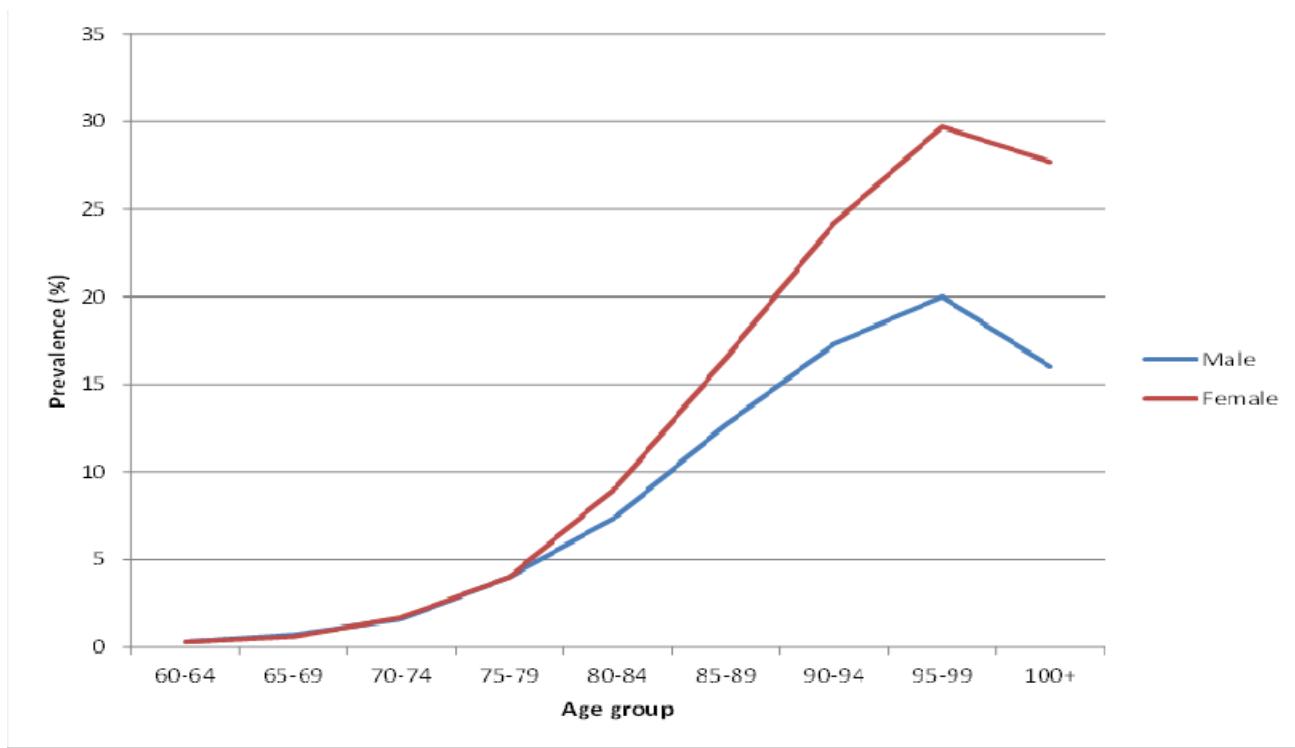
# Older people in England: trends 2005 to 2015

- Between 2005 and 2014 the number of people aged 65+ increased by 18.8% per cent, or by more than 1.5 million people
- The greatest growth in percentage terms was people aged 85+ - this age group increased by 29.3 per cent, or 289,000 people, over that period



Office for National Statistics; "Principal projection – England population single year of age, 2012-based," *Office for National Statistics (2013a)*

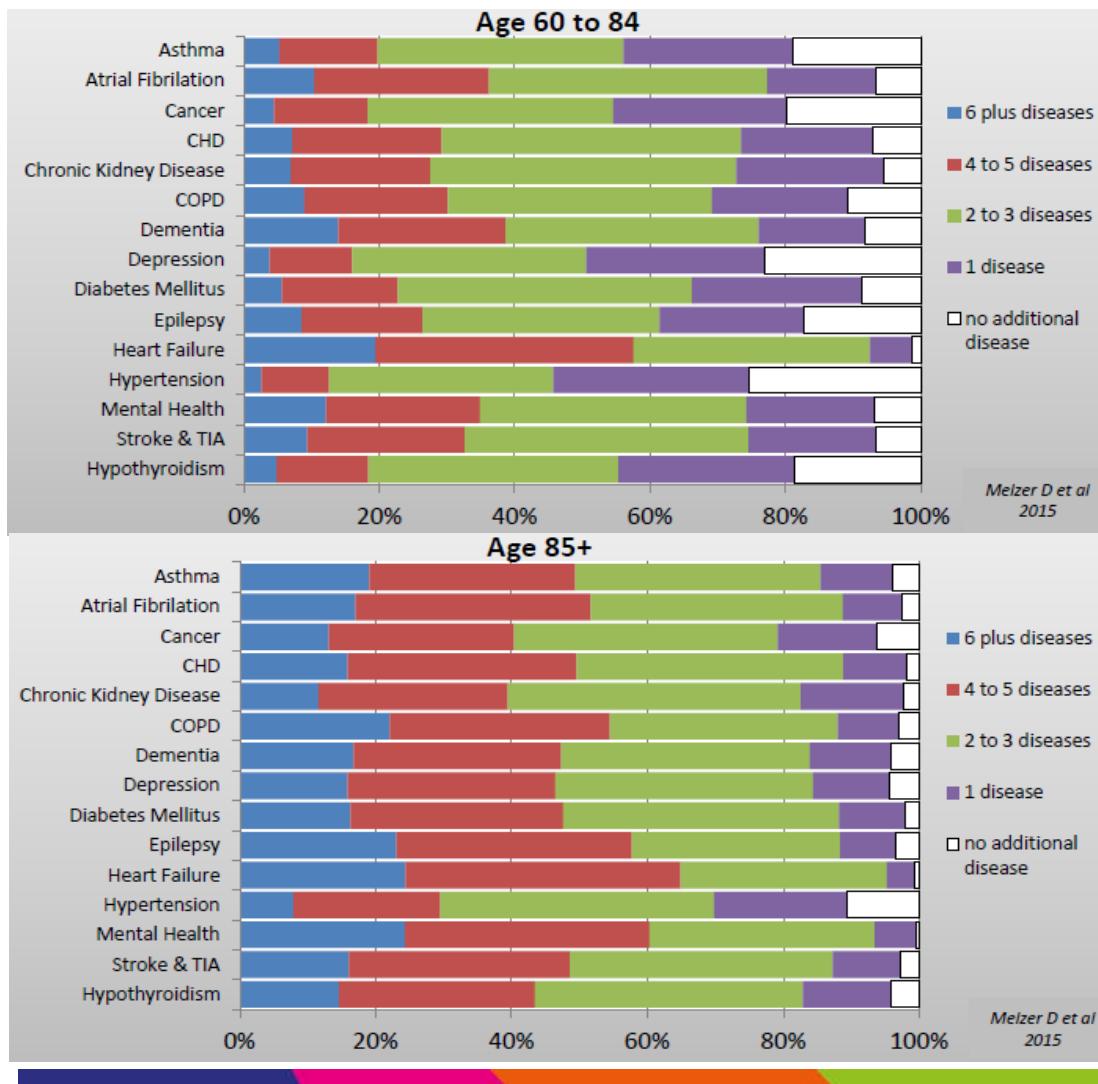
# Prevalence of dementia by age: England, 2015



Age UK and University of Exeter Medical School; “The Age UK almanac of disease patterns in later life,” **Age UK and University of Exeter Medical School**

- Prevalence of dementia is around 4% amongst men and women aged 75 to 79 years old.
- Prevalence then rises steeply in later old age, peaking at 29.7% for women and 20% for men aged 95-99 years old

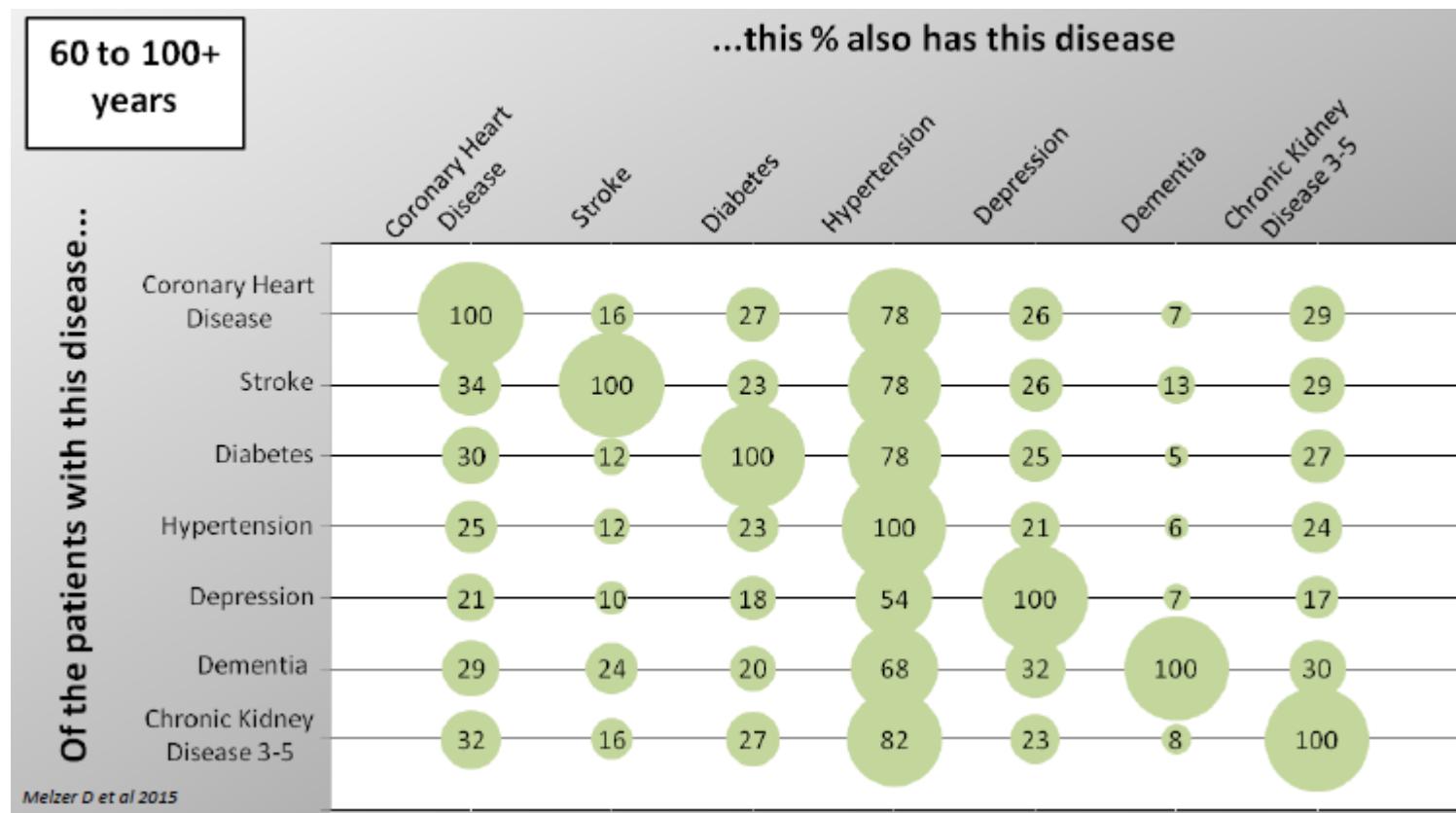
# Dementia and multiple long term conditions



- Amongst 60 to 84 year olds living with dementia, 92% have at least one other condition; 53% have three or more.
- Amongst those aged over 85, the rate even higher.

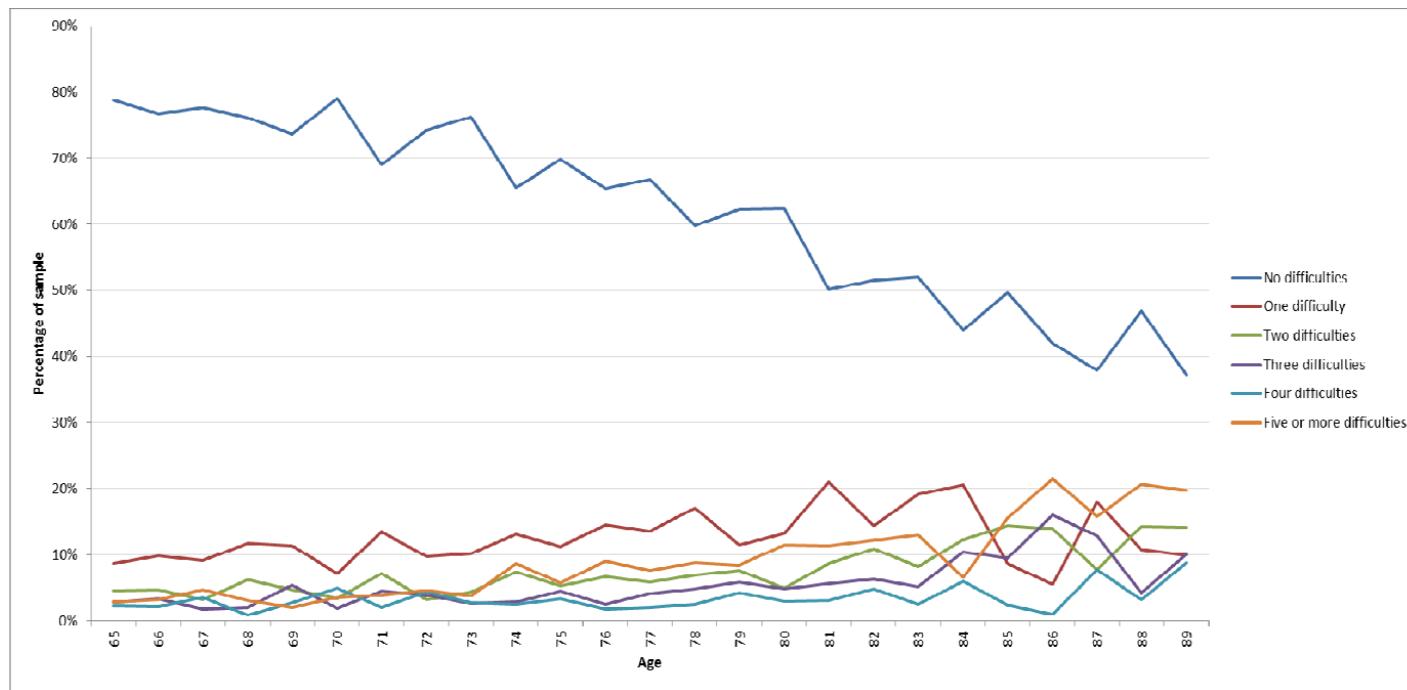
Age UK and University of Exeter Medical School; “The Age UK almanac of disease patterns in later life,” *Age UK and University of Exeter Medical School*

# Common co-morbidities



- These trends are clear amongst 60 to 84 year olds with dementia, 22% also had a stroke, 22% had diabetes, 65% had hypertension and 34% a record of depression.

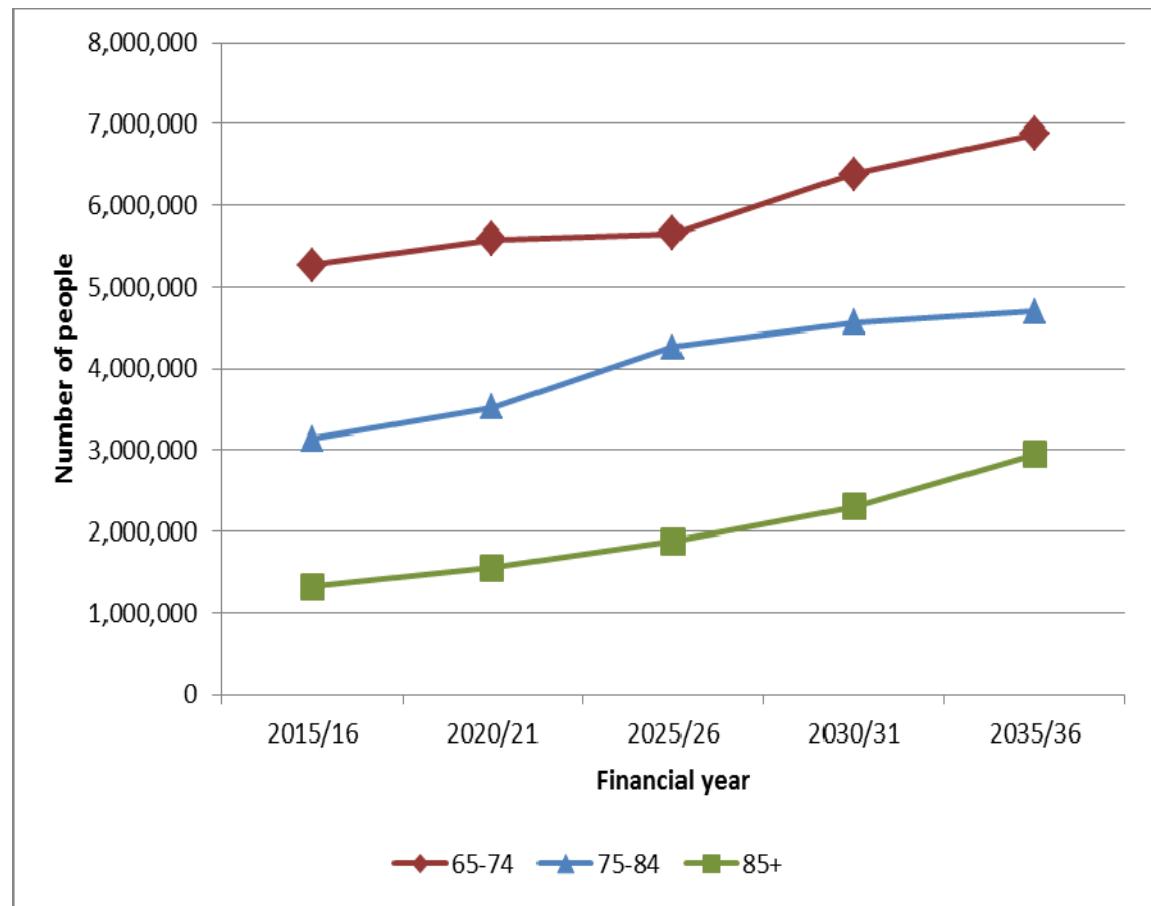
# Difficulties with activity of daily living



Age UK Research analysis  
using Marmot, M. et al.  
, *English Longitudinal Study of  
Ageing: Waves 0-6, 1998-  
2013 [computer file]*. 21st  
Edition. Colchester, Essex: UK  
Data Archive [distributor], July  
2014

- Around 21% of people at age 65 have experience at least one difficulty with activities of daily living. This increases to more than 50% by age 85.
- Amongst people over the age 85 around 20% have difficulties undertaking five or more activities of daily living.

# Population ageing: trends 2015 to 2035

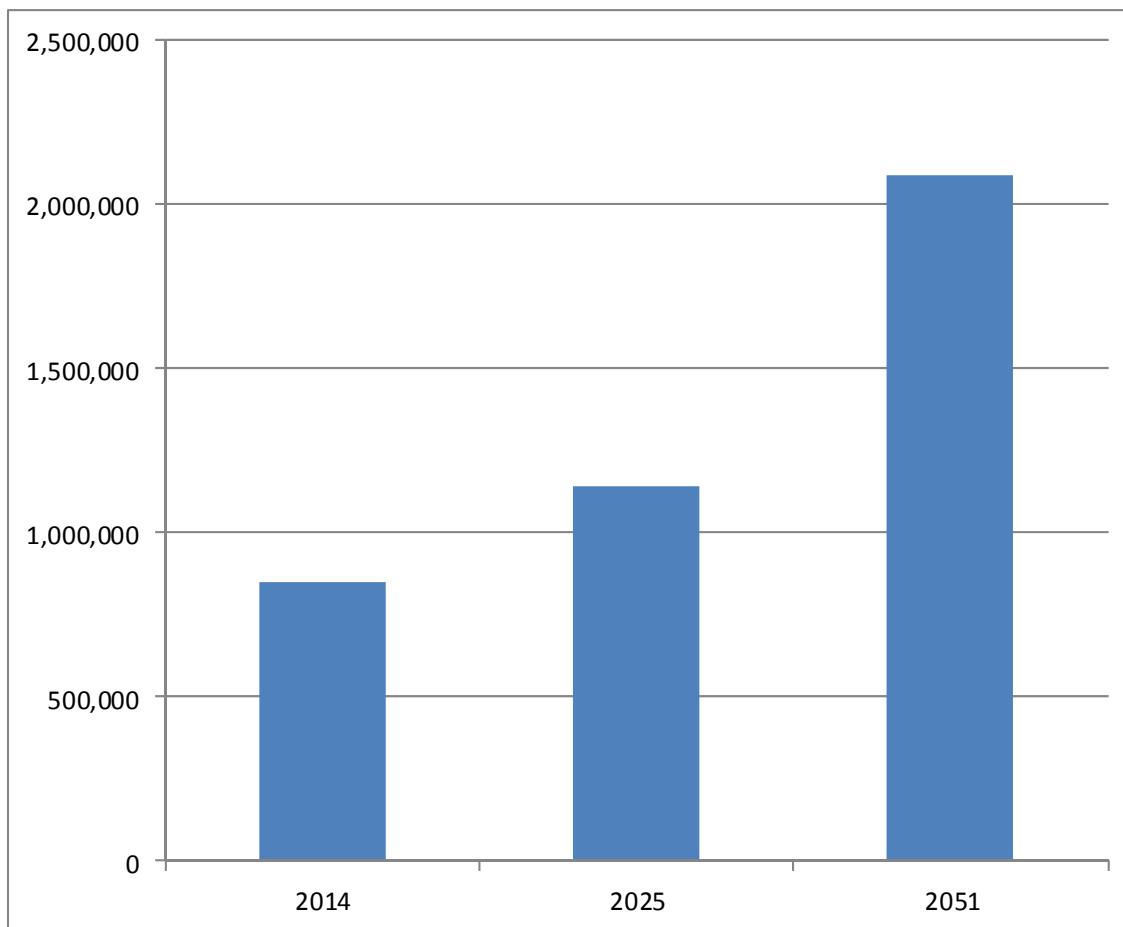


- Between 2015 and 2035 the number of people aged over 65 is projected to increase by 49.2%.
- But people aged over 85 will be the fastest growing group: projected to increase by 122.4%, from 1.3 million to 2.9 million.

Office for National Statistics; "Population estimates for UK, England and Wales, Northern Ireland, mid-2014," **Office for National Statistics**

# Growing numbers of people living with dementia in the UK

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- In 2014 there were an estimated 850,000 people be living with dementia in the UK in 2014, the majority (773,502) were aged 65+.
- By 2025, the number is expected to rise to 1.14 million.
- By 2051, it is projected to exceed 2 million.

Alzheimer's Society, Dementia UK: Update report, November 2014





# What does it mean to live well with dementia?

Perspectives from people living with dementia and their families and carers



# Living well with dementia

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## Living as normal as life as possible

- To be able to retain a sense of ‘normality’ and continue living everyday life for as long as possible

## Socialising, being active and remaining part of things

- To participate, feel part of the community and make a contribution
- To maintain social relationships and engage in activities you enjoy

## Having ‘good health’

- To not be overly-medicalised or medicated
- To manage other limiting conditions or disabilities

## Being able to manage practically and financially

- To be able to manage financially, have appropriate transport, housing etc.
- To have access to service and support



# Living well and caring for someone with dementia

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## Help and support to manage

- To have access to support services delivered by knowledgeable professionals
- To receive timely advice about the condition and what help is available

## Being able to have ‘time for me’

- To be able to go out and keep up activities you enjoy
- To have access to respite care

## Being able to look after yourself

- To have time to exercise and manage your own health

## Social networks and support

- To be able to maintain social relationships and build up peer support networks
- To live in a supportive and understanding community



## Key points for policy makers

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- Access to high quality, coordinated and responsive health and social care services is very important, particularly to carers and family members
- Most people living with dementia will experience other health conditions, so all health and care professionals need knowledge and skills in dementia care
- However supporting people with dementia should be taken into account in many areas of public policy, including:
  - Building dementia friendly communities – enabling people with dementia to live independently and navigate their environment
  - Promoting awareness in the public about dementia and providing extra training for key professions – bus drivers, shop assistants, bank staff etc.
  - Investing in dementia inclusive social programmes – exercise classes/facilities, community centres, lunch clubs
  - Ensuring access to information, advice and practical support – managing finances, adapting housing, technology and aids





## Challenges and solutions

Dementia services and support in the health and care system in England



# A brief overview of the health and care system in England

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## Health care

- The NHS provides **universal, free health care** to the whole population
- The NHS is publically commissioned but provided by a range of public, private and NGO organisations
- Access to services are largely managed by general practitioners in primary care
- There is significant consistency around what is available, but big variations in services and quality

## Social care

- Social care services are the responsibility of local government
- Access to social care is **means-tested and needs-tested** – older people must have high needs and a very low income to qualify
- Social care is provided predominantly by the private sector
- Most older people rely on a mix of family care-givers or paid for care
- There is considerable variation around both quality and availability in different parts of the country



# Challenges in supporting people with dementia

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- Diagnosis rates for people living with dementia are too low – current only around 50% of people receive a diagnosis
- There is huge variation in access and quality of pre- and post- diagnostic support across the country
- The health and care system in England is complex, fragmented and difficult to navigate – especially for people with dementia
- Responsibility for care and costs are often unclear and a source of dispute and delay between hospitals, GPs, community based services and social care
- Too few specialist services and support
- More work needed to ensure all professional staff are trained to support people living with dementia



# Challenges in supporting people with dementia

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- Dementia (unlike other long term health conditions) is largely seen as a ‘social care’ responsibility so the majority of care is provided by family caregivers and care workers in people’s own home, in day centres or in a residential care home
- Because ‘social care’ is not universal, many older people pay for their own care and rely on family and friends – however a large number have insufficient support to meet their needs
- The quality of care is extremely variable and largely provided by unqualified and low paid care workers
- When care that is provided by local authorities is often inadequate to meet people’s needs
- People living with dementia also may not get equivalent access to health care services or support for their other health conditions



## National policy trends

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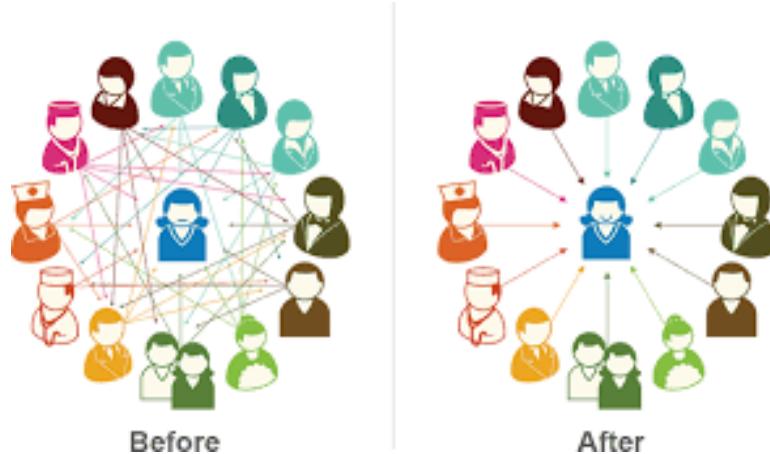
- Promoting dementia friendly communities and ‘dementia friends’ programme
- Promoting ‘risk reduction’ programme through public health initiatives
- Health and social care reform programmes to bring together health and social care services:
  - Personal budgets that enable people to decide their own care needs
  - New models of health care delivery that provide greater support in the community and reduce hospitalisation
  - Greater investment in non-medical approaches to care and support



# Solutions: investing in care co-ordination

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- Age UK Cheshire East provides a dementia specialist wellbeing co-ordinator to work alongside an existing wellbeing co-ordinator team
- The specialist co-ordinator works with people with dementia, carers, health and social care teams, third sector organisations and the wider community to improve early identification and co-ordinate a care and support plan
- Trained volunteers provide on-going low level support to those with dementia – for example weekly telephone calls, companionship, peer support, and accompanying people to appointments and leisure activities



# Solutions: providing additional support at key points in the pathway

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- Age UK Newcastle is piloting ‘Dementia Navigators’ in hospitals
- The ‘Navigators’ work with patients living with dementia, their families and carers to produce a discharge plan
- The plan aims to ensure a safe and supported discharge into the community, working fully with hospital and community staff
- The Navigator will then follow up with the person at home, providing them with support, advice and signposting to other Age UK services and organisations that can provide support



## Solutions: supporting family care-givers

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- Age UK Norfolk provides dementia wellbeing coordinators to support people living with dementia and family carer-givers
- Coordinators help individuals and families to develop the skills and coping strategies they need to reduce the stress of the caring role and them cope with the challenges they face
- The coordinators work with specialist nurses, providing a link with other relevant services



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