# Needs of people with dementia and the need for palliative care

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# Definitions

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•Dementia is a collection of symptoms, inducing a decline in memory, reasoning and communication skills and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.

•Most common in older people. One in 6 people over 80 has a form of dementia and one in 14 over 65 has a form of dementia.

•It is thought that many factors, including age, genetic background, medical history and lifestyle can combine to lead to the onset of dementia.

•Dementia is a progressive condition with symptoms becoming worse over time. Understanding  how this progression happens can be useful in helping someone with dementia anticipate and plan for change.

# Dementia UK 2007 Results

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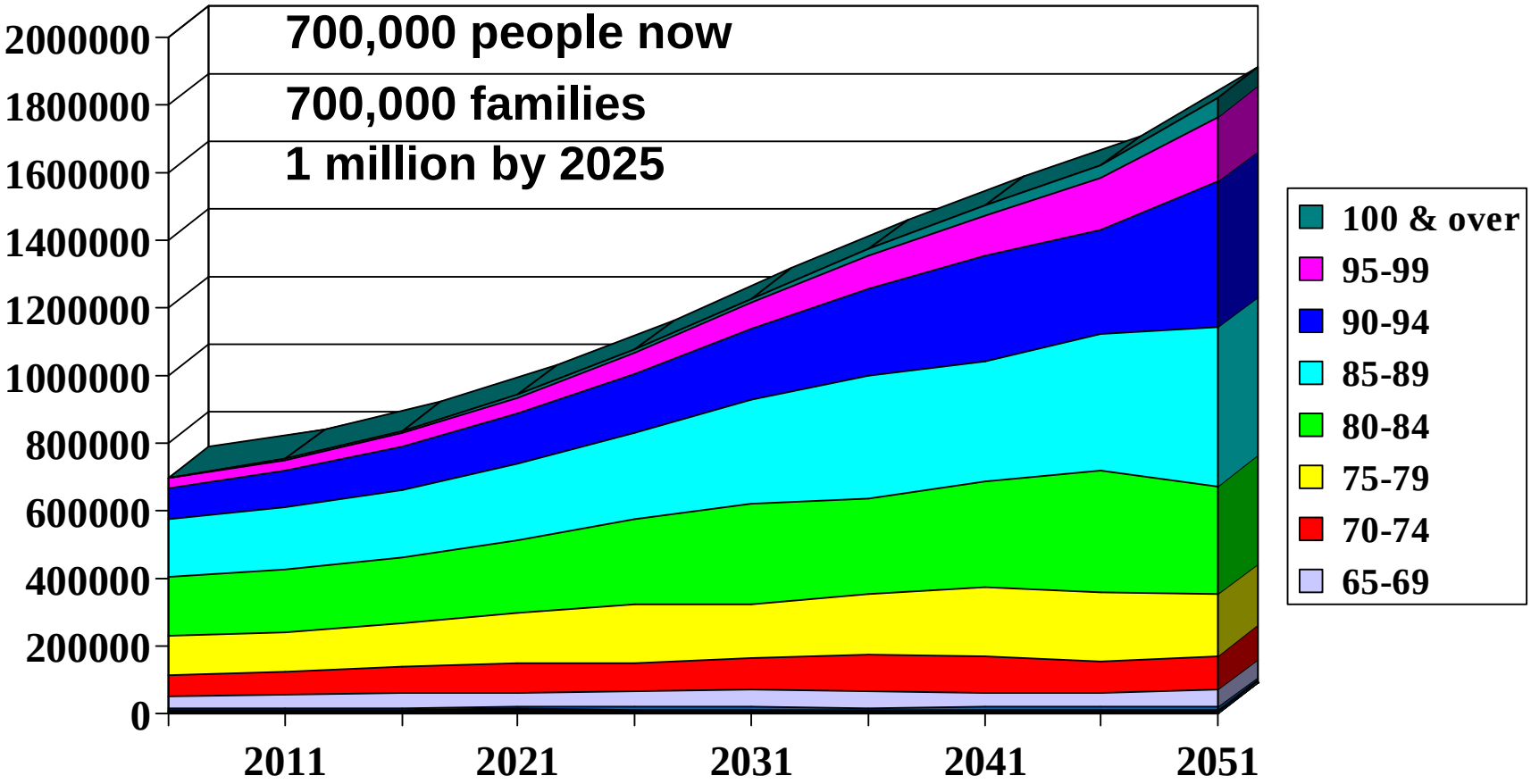
## Numbers of people with late onset dementia by age group



# Dementia subtypes

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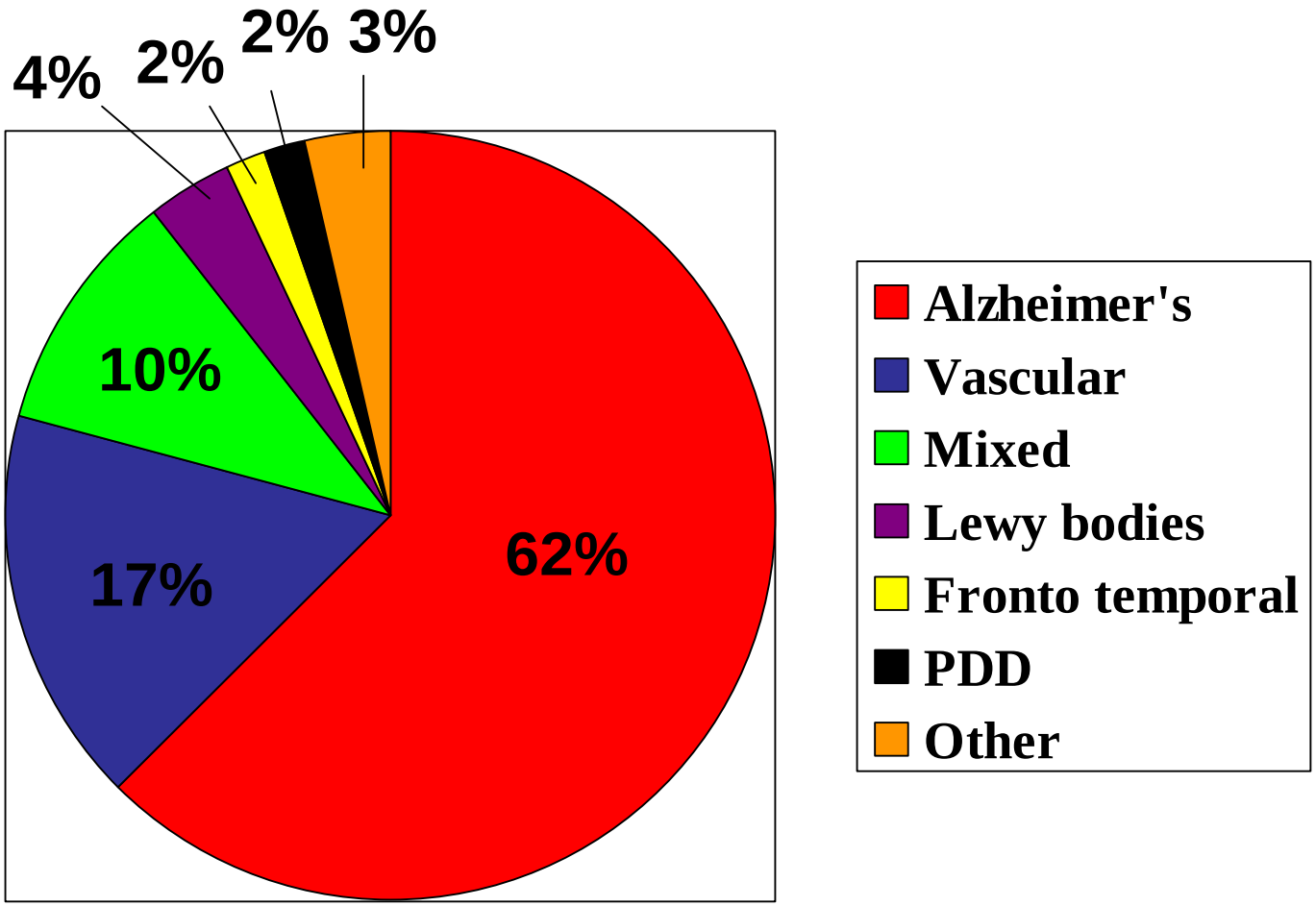
•Alzheimer's disease changes the chemistry and structure of the brain causing brain cells to die. It has a long slow progression

•Vascular dementia is caused by a series of small strokes or small vessel disease which affect the supply of oxygen to the brain. It can cause communication problems, stroke like symptoms and acute confusion.

•Frontotemporal dementia is a rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. People's behaviour can change significantly and they can become disinhibited.

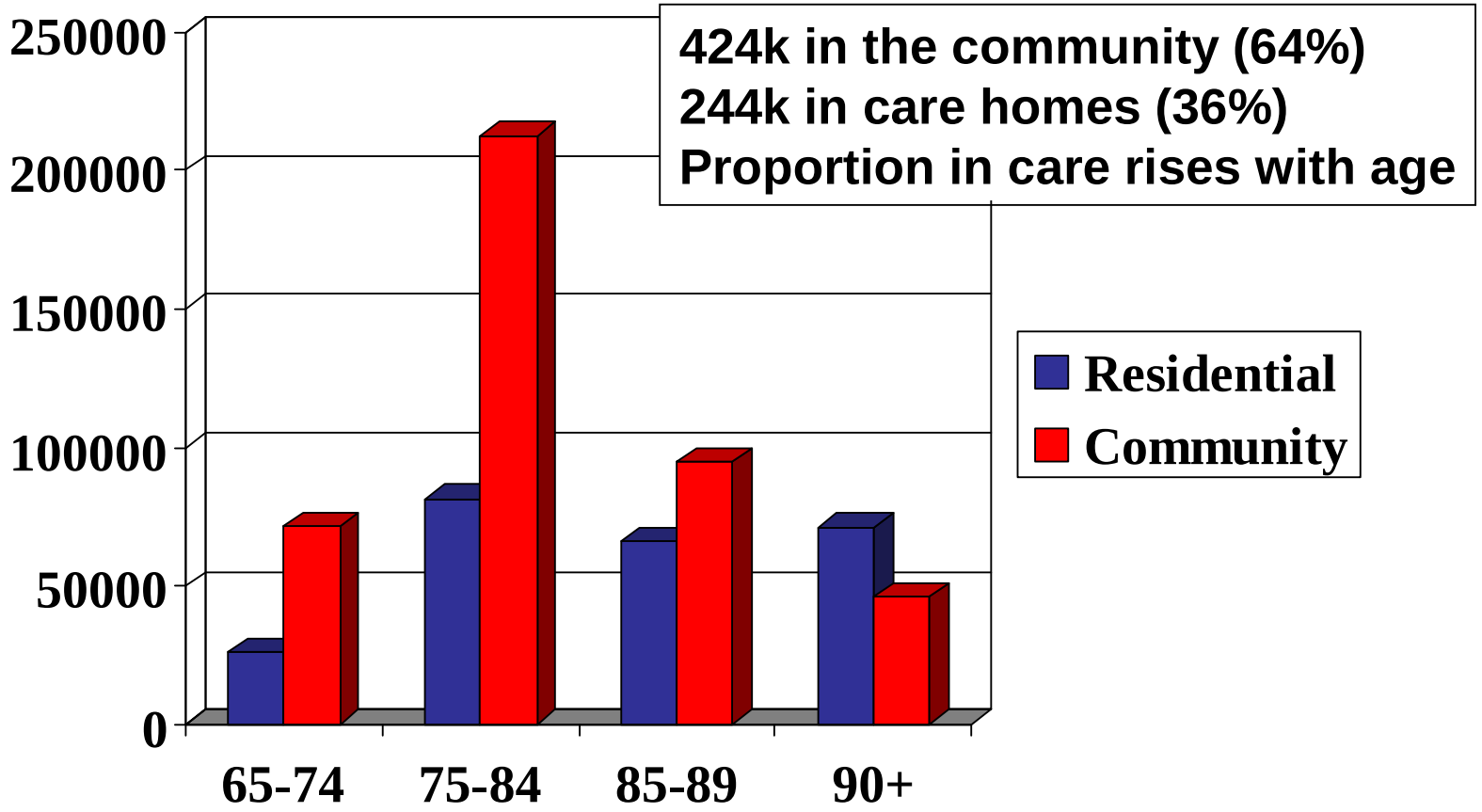
•Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside the nerve cells of the brain. Hallucinations, Parkinsonian tremor and fluctuating abilities are characteristic.

# Dementia UK results



# Dementia UK Results

## Where are people with dementia?



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- **Dementia at the population level**
- **Needs of people with dementia - Individual level**
- **Need for palliative care**
- **Prevalence of dementia in the last year of life** (Source:Exploring palliative care for people with dementia, NCPC, 2006.)

| Age | 65-74 | 75-84 | 85+ |
|---|---|---|---|
| **Cancer** | | | |
| Deaths | 33305 | 43330 | 204070 |
| dementia | 977 | 3800 | 5951 |
| % dementia | 2.9% | 8.80% | **29.1%** |
| **Circulatory** | | | |
| deaths | 315484 | 71469 | 67962 |
| dementia | 941 | 6319 | 19992 |
| % dementia | 3.00% | 8.80% | **29.40%** |
| **Respirat.** | | | |
| deaths | 9615 | 21019 | 18239 |
| dementia | 283 | 1817 | 5224 |
| % dementia | 2.90% | 8.60% | **28.60%** |

# Making a case for palliative care at an individual level

- People with different dementia have different/individual needs (AD/VAD/DLB/FTD)
- Older people – the majority of people with dementia – have different and more complex needs – WHO 2004
- Most commonly affected by multiple medical problems
- Cumulative effect of these may be greater than any individual disease
- At greater risk of adverse reactions and iatrogenic illness
- Minor problems may have a greater cumulative psychological impact
- Problems of acute illness may be superimposed on physical/mental impairment, economic hardship and social isolation and
- There is a tendency  for under assessment and under treatment of symptoms compared to younger people

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# Symptoms of severe dementia

- Significantly disabled and very highly dependent on others
- No noticeable memory ability
- No functional ability
- Incontinence
- No effective communication ability
- Sporadic episodic challenging behaviours.

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# Communication

- **Loss of communication**
- During the middle and later stages of dementia communication can become extremely difficult
- The person with dementia is less competent cognitively and verbally
- Many patients can convey important needs through body language and behaviour changes which should be looked for
- Symptoms of pain and discomfort should be actively looked for and treated with opiates as appropriate.
- Facial expression, tense body language, fidgeting, perseverant verbalisation, verbal outbursts

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## Physical needs

**Symptoms last longer than cancer and the levels of care needed are higher (Lloyd-Williams and Payne, 2002) showed that patients with end stage dementia had a number of symptoms for which they did not receive effective palliative care.**

## Pain

**Assessment of Discomfort in Dementia Protocol shows that the needs of people with advanced dementia can be discerned and treated.(Kovach, 2003). Other tools valuable such as PAINAD, Doloplus, Abbey Pain Scale.**

## Analgesics

**Variety of drugs that can be used from paracetemol to NSAIDs to treat musculo-skeletal pain. The drug of choice and delivery will be influenced by the severity of dementia, level of dysphagia and closeness to death. Patients with dementia are probably more sensitive to these drugs. Discussion with carers /relatives will be crucial.**

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## Swallowing, eating and drinking

- Dysphagia can increase the risk of oral conditions.
- Food For Thought report (Alzheimer's Society , 2000) some 80% of people with dementia were reported to suffer from eating difficulties
- Work with terminally ill people with dementia at home has shown that good food and skilled carers will often reduce or obviate the need for medical dietary support.

## Artificial hydration and nutrition

Has been shown that with in-patients with end stage dementia, artificial feeding neither reduces the risk of aspiration pneumonia, infections or pressure sores, nor offsets the effects of malnutrition(Finucan et all 1999)

## Infections

End stage of dementia is a time when a person is particularly vulnerable to infection and identifying the causes of infection in people with dementia is difficult.

## Psychological needs

•Feelings of loss and bereavement,
•Chronic trauma related to separation, loss, powerlessness, displacement.

## Depression and Antidepressants

Depression is common during the early stages of dementia and the incidence is high in advanced dementia. Antidepressants are therefore essential .It may be prudent to continue with these medications in advanced dementia.

## Psychosis:

Cannot distinguish between reality and imaginary and can affect up to 40% of people with dementia.

## Antipsychotics

Can be effective in small doses but can cause increased risk of stroke and progressive cognitive impairment(Ballard 2005) Helpful to some people but also of harm to others. The House of Commons all Party Parliamentary Group on Dementia is currently reviewing their use.

## Behavioural needs

•Behaviour disturbance, which includes delusions, hallucinations, aggression, wandering, disinhibition may occur in up to 90% of people with dementia at some stage in their illness (Robert et al 2005).

•It has been shown that greater use of psychotropic medication is related to less use of analgesics(Cohen-mansfeild et al 2001). This may mean that people with dementia duffer unnecessary and preventable pain.

## Sedation

•Anecdotal evidence of an episode of lucidity occurring immediately prior to death in patents with advanced dementia is an argument in favour of a non-sedating approach to people at this stage.

•Medication should therefore be used after good discussion and clear information as to the purpose and risks associated with its use.

# Spiritual needs

**The spiritual life of a person is not ended by a diagnosis of dementia**

**Spiritual care goes beyond attention to religious practices, although there is still a need to ensure that any person with dementia for whom religious practices such as attendance at services, reading holy books or prayer is important are enable still to participate.**

**A broader approach to spiritual care has been suggested by Barrance(1996) whose proposals include:**

- **fostering a sense of identity**
- **encouraging a sense of belonging and security;**
- **giving and receiving affection**
- **Respecting the need for space, privacy and dignity**
- **Being alongside in times of distress**

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# Supporting relatives

•Carers of people with dementia experience greater strain, distress and higher levels of psychological morbidity than carers of other older people

•Early and ongoing discussions around end of life care between staff and family are essential

•Although uncertainty is a common feature of dying with dementia, 'not knowing' is something carers find particularly hard to deal with

•Good palliative care relies on active listening to everyone involved and including family and carers in decisions about care

•It is also important that staff help carers to understand that while their views will be considered they do not have responsibility for end of life decisions

•Carers need access to:-

- •An 'information prescription' – signpost carers to sources of info and advice
- •Short-term, home-based emergency respite care
- •An expert carers programme

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# Care homes and the Alzheimer's Society

Quality Care team has developed a wide range of resources on dementia for care homes

•The Society support a specialist accredited trainers network of over 30 trainers who have extensive experience of dementia care and training.

•Much in these resources emphasises a person centred approach to dementia care - also key to palliative care

•For more information contact Quality Care Team tel 01904 633 581 email quality@Alzheimer's.org.uk

Website : www.alzheimers.org.uk

Helpline: 0845 300 0336

# In conclusion - sharing the care & learning

- High proportion of people with a variety of conditions experiencing dementia highlights need for all generalists and specialists to understand and manage dementia.
- Way forward is to enable people to be cared for where they wish to be so need to share experience, training and care
- Its not about specialist palliative care doing it all but involves:
  - All care settings including housing, care homes, hospitals
  - All professional careworkers