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The role of care homes in palliative and end of life care

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The role of care homes in the palliative and end of life care

- Older people have been living and dying in Care Homes for many decades. But as life expectancy has extended and those who live longer lives do so largely in functional good health for much longer, the demography and epidemiology of dying and death have changed dramatically.

- The latest available UK data provide strong evidence of the rising numbers of old age deaths in Care Homes and previously unavailable material on the causes of those deaths.

- A new and important picture emerges, which needs to be central to discussions about policies and practices for end of life care. It reveals distinctive patterns of multiple co-morbidities now bundled together as **frailty**, which require revised patterns of end of life care that rely more on sustained support rather than medical interventions or elaborate palliation.

- In addition **dementia** has become the principal cause of death in the UK and nearly 60% of those deaths take place in care homes.
- **These trends are also present in Malta** and whilst they are signalled in the *Malta Active Ageing Policy 2014-2020,* they demand more attention and new practices to improve the last lap of life

During 2015 there were 3443 deaths in residents of Malta, reflecting the postponement of death to older age groups.

68.9% of deaths occurred within a hospital with 53.3% occurring at Mater Dei Hospital.

Circulatory diseases including heart diseases and stroke accounted for 38.7% of all deaths while cancer deaths accounted for 27.2% of all deaths.

Trends in major causes of death including heart disease, stroke and diabetes are showing a downward or stable trend, however mortality rates for Malta are higher than the EU average.

Trends in standardised mortality rate due to lung cancer in women, dementia in both sexes and suicide in males are showing an upward trend. However mortality rates from these causes in Malta is lower than the EU average.

Conditions such as dementia, pneumonia and diabetes are important causes of death in the older age groups.

End-of-life Care: Malta & Gozo

Policy recommendations

• Improving the training opportunities in end-of-life and palliative care for persons working in the social and health care sectors.

• Creating legislation to introduce advance directives for health care.

• Developing and implementing policies and procedures in health care facilities concerning end-of-life issues, including, but not restricted to, artificial feeding and resuscitation, on admission to the facility by a suitably qualified health practitioner.

(National Strategic Policy on Active Ageing: Malta 2014-2020 p.79)

MALTA Annual Mortality Report 2015
Department of Health Information & Research

Deaths in the 65-84 age group

There were 1702 deaths in this age group accounting for 49.4% of all deaths. There was an increase of 36 deaths from 2014.

Commonest causes of death in persons 65-84 years Deaths in the 85+ age group There were 1174 deaths in this age group accounting for 34.1% of all deaths. There was an increase of 120 deaths from 2014.

Circulatory diseases predominate in this age group. However, other conditions including dementia, respiratory infections and diabetes were important causes of mortality in older persons (table 9).

Deaths in the 85+ age group

There were 1174 deaths in this age group accounting for 34.1% of all deaths. There was an increase of 120 deaths from 2014. *Circulatory diseases predominate in this age group*.

However, other conditions including dementia, respiratory infections and diabetes were important causes of mortality in older persons (table 9):

Commonest causes of death in persons 85 and over

Ischaemic heart disease	25.3
Cerebrovascular disease	10.1
Other heart diseases	8.7
Pneumonia and other acute lower respiratory infections	8.5
Dementia	**7.7**
Diabetes mellitus	4.1

Figure 5: percentage of deaths in persons over 65 years by place of death

4 out 5 deaths take place in hospitals

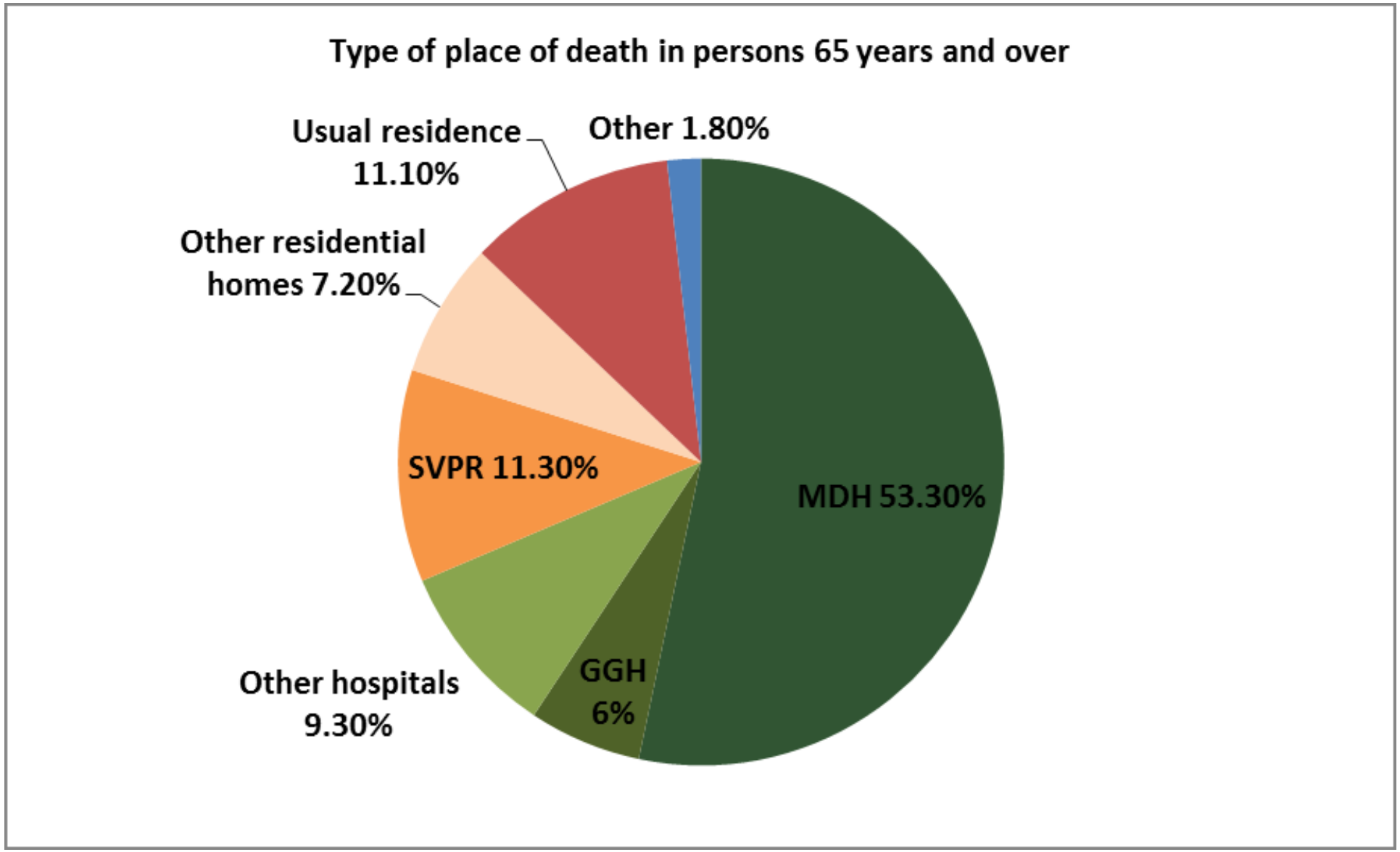
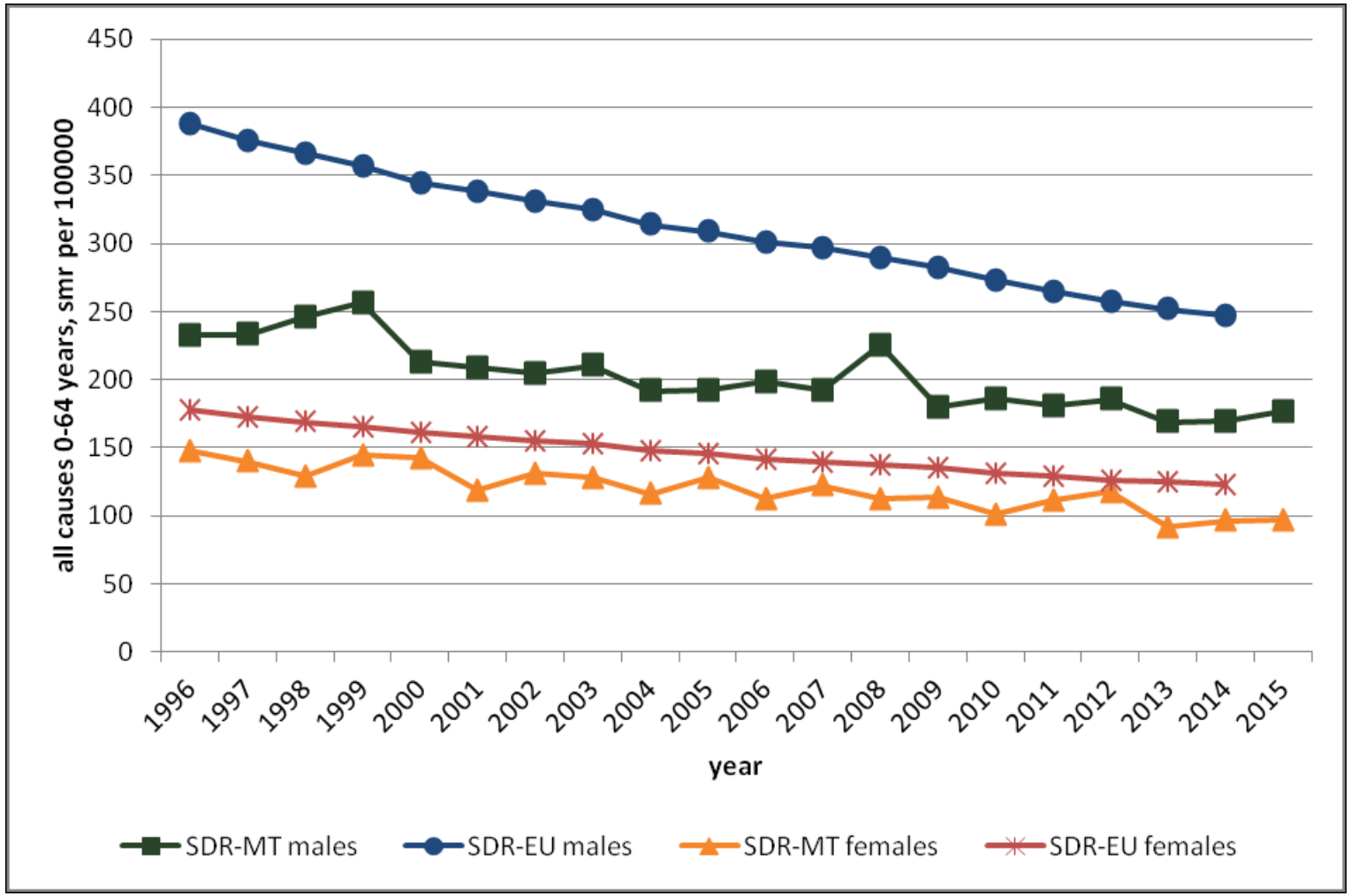


Figure 2: Trends in standardised mortality rates in males and females 0-64 years in Malta compared to the EU average[2]

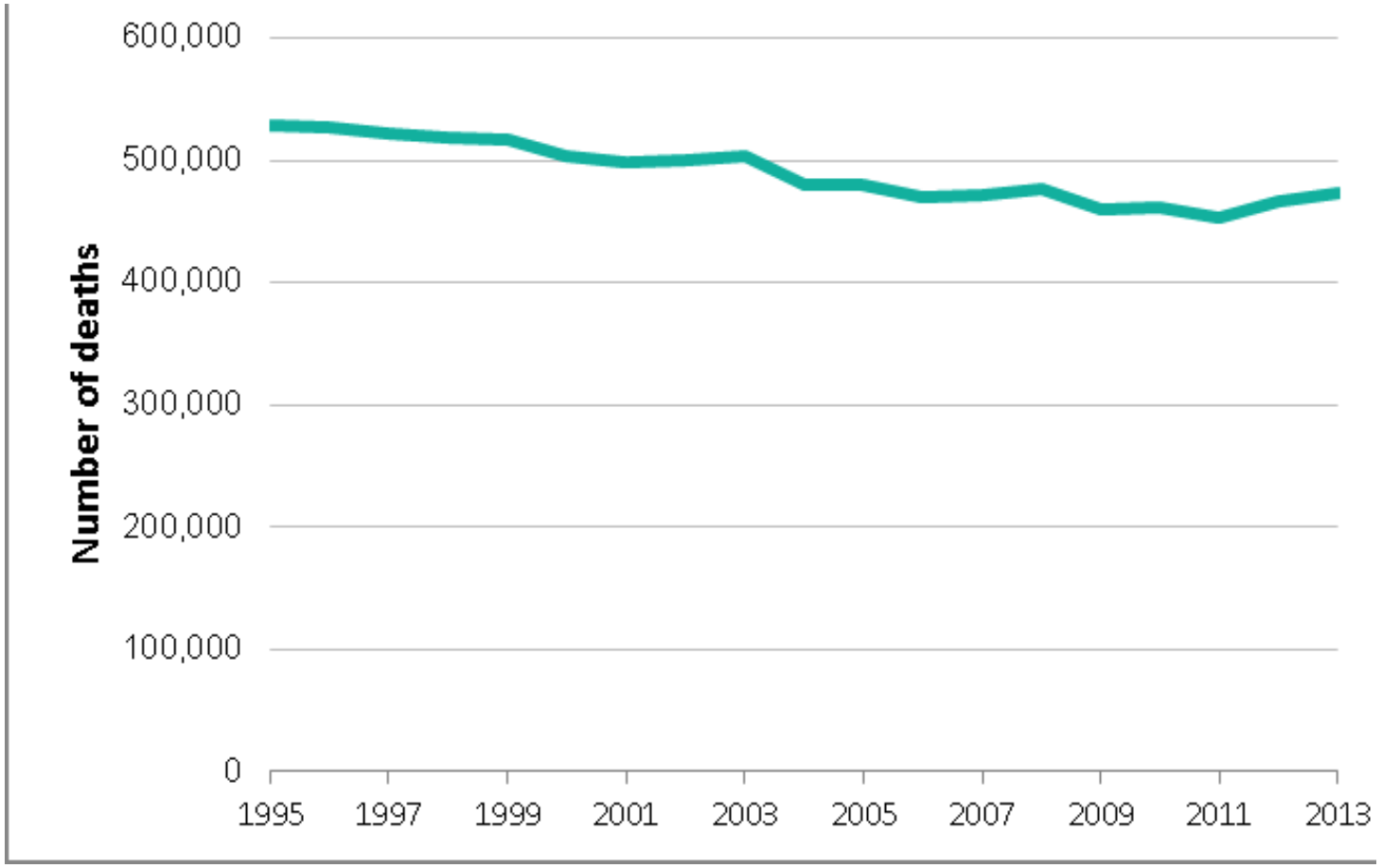
Standard mortality rates for men and women in the age group 65+ in Malta are similar to the EU average.



Death in the province of Old Age

- For the first time in human history the overwhelming majority of deaths are of ‘older’ people.
- Older people have been living and dying at home, in hospitals and in Care Homes for many decades. But as life expectancy has extended and those who live longer lives do so largely in functional good health for much longer, the demography and epidemiology of dying and death have changed dramatically.
- Premature deaths are greatly reduced to the point where 84% of deaths in England in 2013 were people 65+.
- 75% of all deaths are of people over 75, 39% were 85+.
- All too many of those individuals (48%) end their lives, unsatisfactorily and at considerable public cost, in hospitals. A further 25% die at home and 6% in hospice care.
- The medicalisation of death, is costly, often inappropriate and undignified.

Trends in deaths in England 1995-2013



Concentration of deaths in old age, 2013

- 84% of deaths were of people aged 65 +
- 39% were of people aged 85+
- Almost half of women dying (48%) were age 85 +
- Will be rising in the early 2020s

One in four (non accidental) deaths are in Care Homes

- The proportion who die in Care Homes has risen from 16% in 2004 to 22% in 2013 (NEoLIC).

  From 78,867 to **101,991 deaths.**

- This is in part due to the later age and health status of entering Care Home residents (average age circa 89 years) and notably to the expansion in the numbers of 'temporary residents', who are placed in Homes in the diagnosed expectation of imminent death.

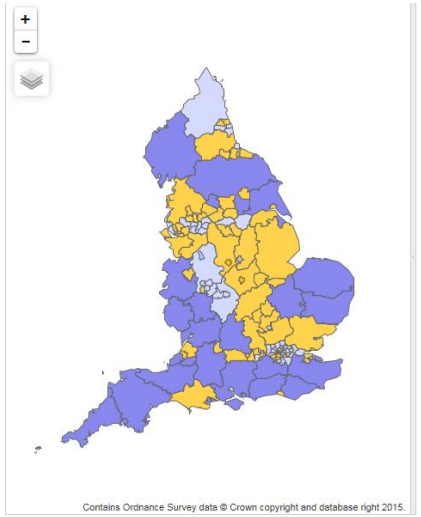
- As Palliative and End of life Care (EoLC) only applies to those known to be dying, it is important to exclude the **annual 8% of deaths from accidents.**

- Using this reduced base of deaths; those which take place in Care Homes

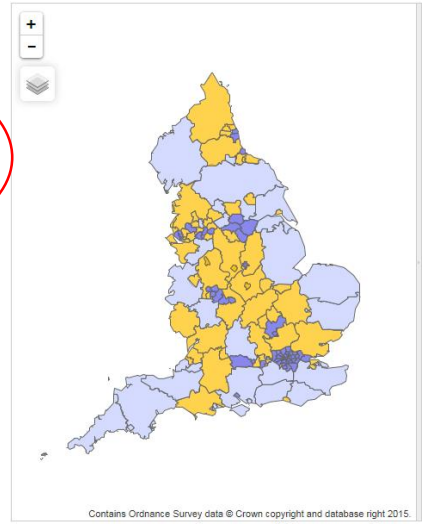
  are just short of 25% of all deaths and **for the over 85's it is 36.7%**

Where people aged 85+ years die in England

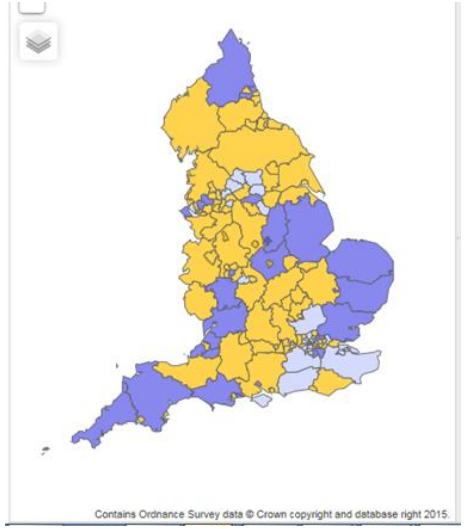
Hospital
45.6% ↓



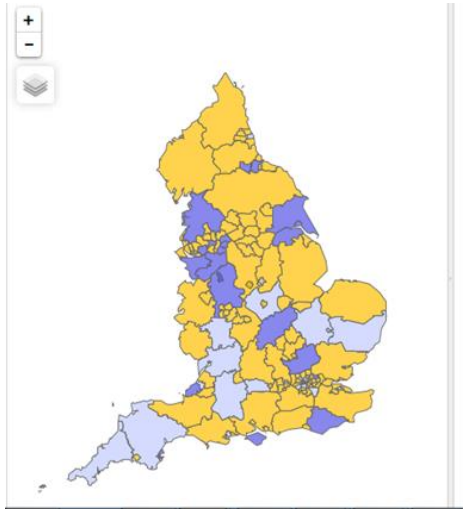
Care home
36.7% ↑



Hospice
1.92% ↓



Home
14.8% ↓



Living the last lap

- Death and dying are a constant presence in the life and work of care homes. The great majority of persons who enter a care home in the UK, will, after an average stay of around 18-20 months (nursing homes) or 30 months (residential/social care homes/ assisted living), die there. The care home is therefore potentially the setting for the last major event of each resident's life.

- Standard practice in the UK care homes sector, for a very long time, had been for older people with life threatening illnesses (advanced cancers, severe strokes, complex respiratory illnesses in particular) to be admitted to hospital in the belief that these conditions require medical / nursing skills and facilities unavailable in care homes.

- In the past there was some justification for this set of assumptions. Care homes – both residential and nursing - had less well qualified staff, they had very little specialist equipment.

Living the last lap

- Most older people who die in or from care homes do *not* present complex symptoms as life closes. The epidemiologically based trajectories towards death, produced by **Lynn and Adamson (2003)** demonstrate the predominance of the long slow decline and clinically uncomplicated dying.

- Moreover, most care homes wish to enable their residents to remain in the home until they die and often succeed in providing calm, caring and personal care in a familiar environment where relatives and friends can share intimate last things.

- To be able to die in familiar surroundings is a strongly stated preference. Yet, too often the GP will send the older person off to die in the alien, clinical setting of the hospital, where intimacy is virtually impossible.

- People who live with dementia become anxious and confused when removed from their familiar environment. So enabling them to die among people and carers that they know is -as in a care home- is optimal. Transfers to hospital settings are to be avoided whenever possible.

Unthinking practices

- It therefore makes sense to develop policies and practices which address dying and death as integral, open and positive features of care home life.

- At present, basic practice involves asking new residents and their relatives if they have a will, what their religion is, who their next of kin is, do they wish to be buried or cremated and have they got any funeral plans.

- These are daunting and dismaying questions to be asked within a week of losing your home. Commonly these topics are never raised again with the resident.

Life Reviewing

- It is evident from gerontological research that most older people find that the opportunity to engage in sensitively facilitated life review is helpful and positive. It enables individuals to resolve the concerns they have about whether have fulfilled their own expectations and those of others.

- Not surprisingly, it is common for people to feel their journey through life has been one of failings and inadequacy (Coleman et al, 2002; Atchley, 2009).

- As the end gets closer the anguish this causes can develop into what I have termed ***biographical pain***. (Johnson,2002, 2010). It is a rarity for residents in care homes, or indeed any older people, to have the opportunity to talk, safely, about their life or their death.

Biographical Pain

- Biography is the key source of spirituality
- Remembering in pain is a special version of spiritual reflection for the very old and frail
- Biographical pain is:

  'The irredeemable anguish, which results from profoundly painful recollection of experienced wrongs which can now never be righted.

  When finitude or impairment terminates the possibility of cherished self promises to redress deeply regretted actions'.

- This is an important part of the study of ageing and the lifespan.

National Homes Training programme

105 Residential and Nursing homes in England

OBJECTIVES

- To establish a higher level of awareness, skill and good practice in helping residents to consider the close of their lives and how they (and their relatives, if this is the resident's wish) would like their end of life care, funerals and memorials to be.

- To provide home managers and staff with the knowledge and competences, to ensure that as many residents as possible (and who wish it) should be able to die 'in place', in the home; supported by staff, external professionals, relatives and significant others.

- To enable all Homes to develop general guidelines and protocols to help staff carry out sensitive, positive and resident-centred support; within a more developed set of company requirements for end of life care.

Death and Dying in Care Plans

- Incorporation of End of Life Care protocols in company/ Home Assessment Tools and Care Plans is clearly the foundation of good practice. It makes care and support of the dying older person ‘essential’ and ‘authorised’ work. The indicative evidence is that many homes made only minimal reference in their Care Plans to dying and death.

- Despite the evidence that homes provided sketchy policies and records, there is much evidence of very positive motivations and good ‘common sense’ care and provision for relatives.

- Positive motivations and good ‘common sense’ care and provision for relatives.

- *Whilst care home staff are amongst the least educated in the workforce, their combination of positive motivation to care and the life experience they bring is an under valued and under explored resource*

Feedback from Staff

- *An independent feedback and evaluation of the training was conducted. What follows is a small selection of what participants chose to say.*

Communication

- Many staff are afraid that giving information about a resident's impending or actual death is a breach of confidentiality. This leads them to avoid the subject or to avoid answering questions directly. "We never said she'd died. We didn't talk about it. Residents are interested in who's died. Perhaps it's us staff who don't want to talk." (Manager)

- A policy change enabling death and dying to be referred to more openly was frequently positive:

- "It is nice to be told when a resident has died because we just miss them and wonder where they are and don't like asking what's happened" (Relative)

Establishing wishes for funeral and terminal care

- A home that took part in the pilot project had devised a questionnaire for relatives of newly admitted residents (many with dementia). In training sessions it was clear that most residential home staff did not like filling in the individual life style agreement section on death, and it was often left blank. Equally it was noted that the section was extremely small and needed to be expanded with more specific questions.

- “We now talk more to residents, especially at bath times; there are fewer superficial comments; people are much happier to talk about death.” (Care Assistant)

Saying goodbye

- One obvious benefit of more open communication is that staff and residents have a chance to say goodbye. “In the past you didn’t tell other residents someone was terminally ill. You’d just say “She’s poorly”. Now it’s much more open. Friends are allowed to visit the person before and after their death.”
- Most homes now encourage staff and residents to attend the funeral.

Removal of the body

- In the training sessions, several participants felt the death taboo was particularly in evidence in practices concerning removal of the body. On reflection participants felt certain practices such as removing a body via the back door, could amount to disrespect.
- One home has initiated standards for funeral director procedures after being distressed by seeing a dead resident being treated like a carcass. Their policy states “There will be no closed doors, or removal in secrecy and the deceased resident will leave through the front door.”

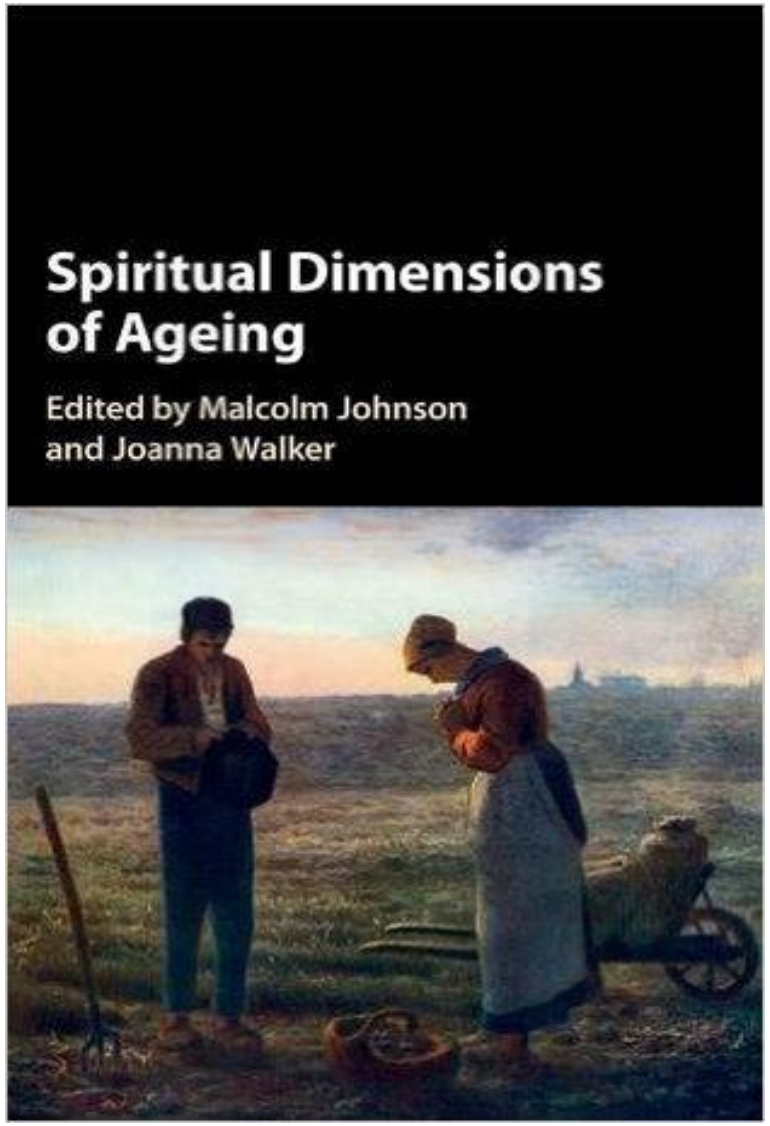
Conclusions

- Death is not a medical event

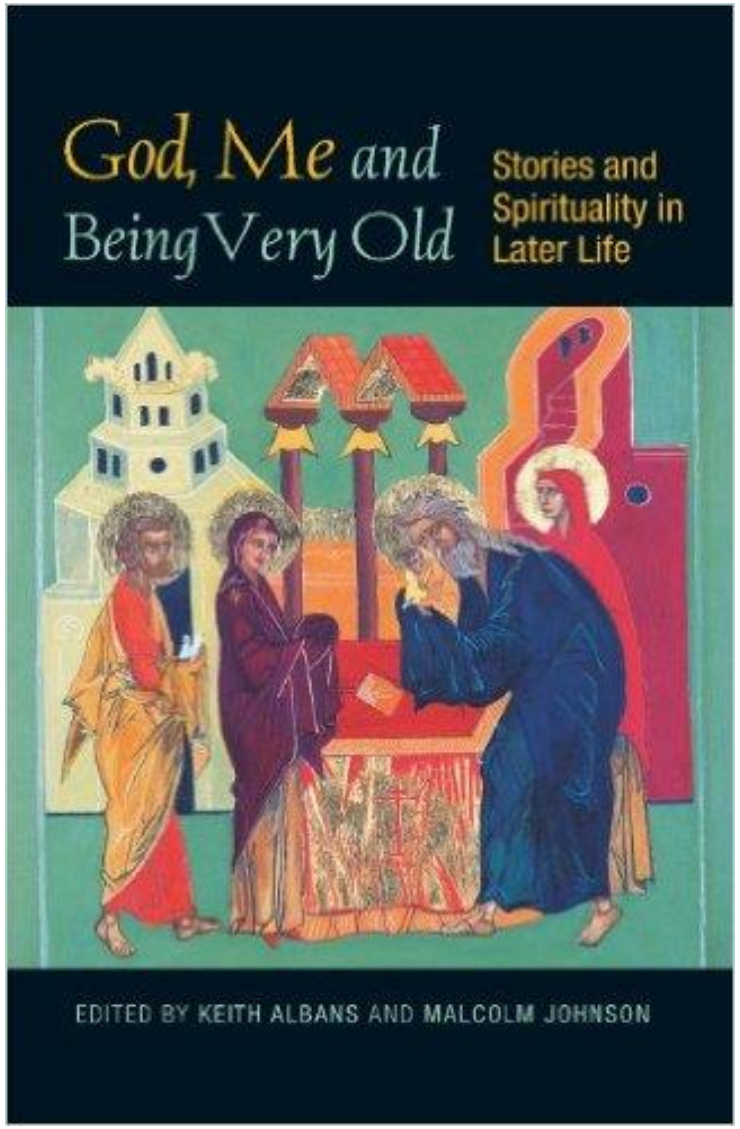
- Staff of care homes are systematically under-rated by those who are unfamiliar with the nature and difficulty of their daily tasks. Yet we learned in the discussion groups, of all manner of excellent care services provided to dying residents. Their explanations were routinely simple and caring. ‘We treat them as if she was our own mother’.

- Of course some of these ‘experiential’ practices were inappropriate. But when this view was addressed and explained, trainers rarely encountered resistance to what was suggested as better or safer ways. Unlearning seemed easier for the staff of care homes than for equivalent trained professionals.

- Good end of life care in care homes enables dignity, familiarity with carers and the physical environment. It also allows family and friends the space, privacy and support they need.



Cambridge University Press, December 2016



SCM Press 2013