

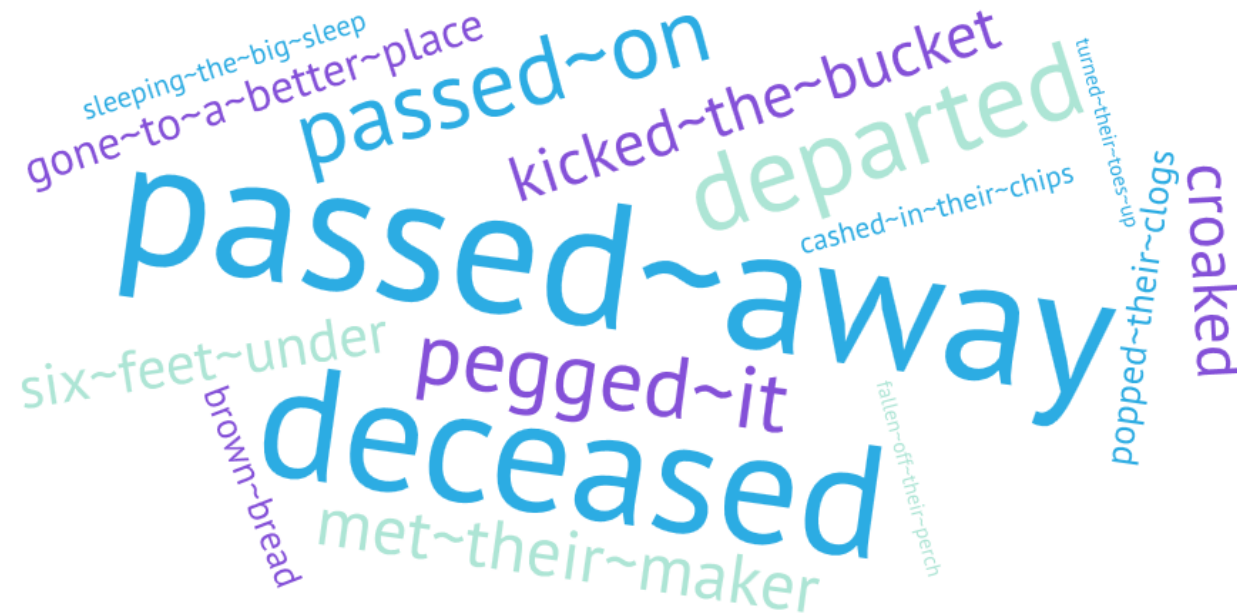
Living well until the end-what can palliative care offer people with dementia ?

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Overview

- What is palliative care?
- Why is palliative care important ?
 - For society
 - For individuals
- What can it offer people with dementia, their families and friends

Let's talk about it!



(Richard Smith and Nataly Kelly: Global attempts to avoid talking directly about death and dying BMJ, 2012)

What isn't palliative care!

- NOT withdrawing active treatment or care
- NOT a pathway that ends in death
- NOT just for the last few weeks of life
- NOT just for people with cancer
- NOT just delivered by palliative care teams
- NOT only given in hospices

What is palliative care?

*“The **active total care** of patients whose disease is **not responsive to curative treatment**.*

*Control of **pain**, of other symptoms, and of **psychological, social and spiritual** problems is paramount.*

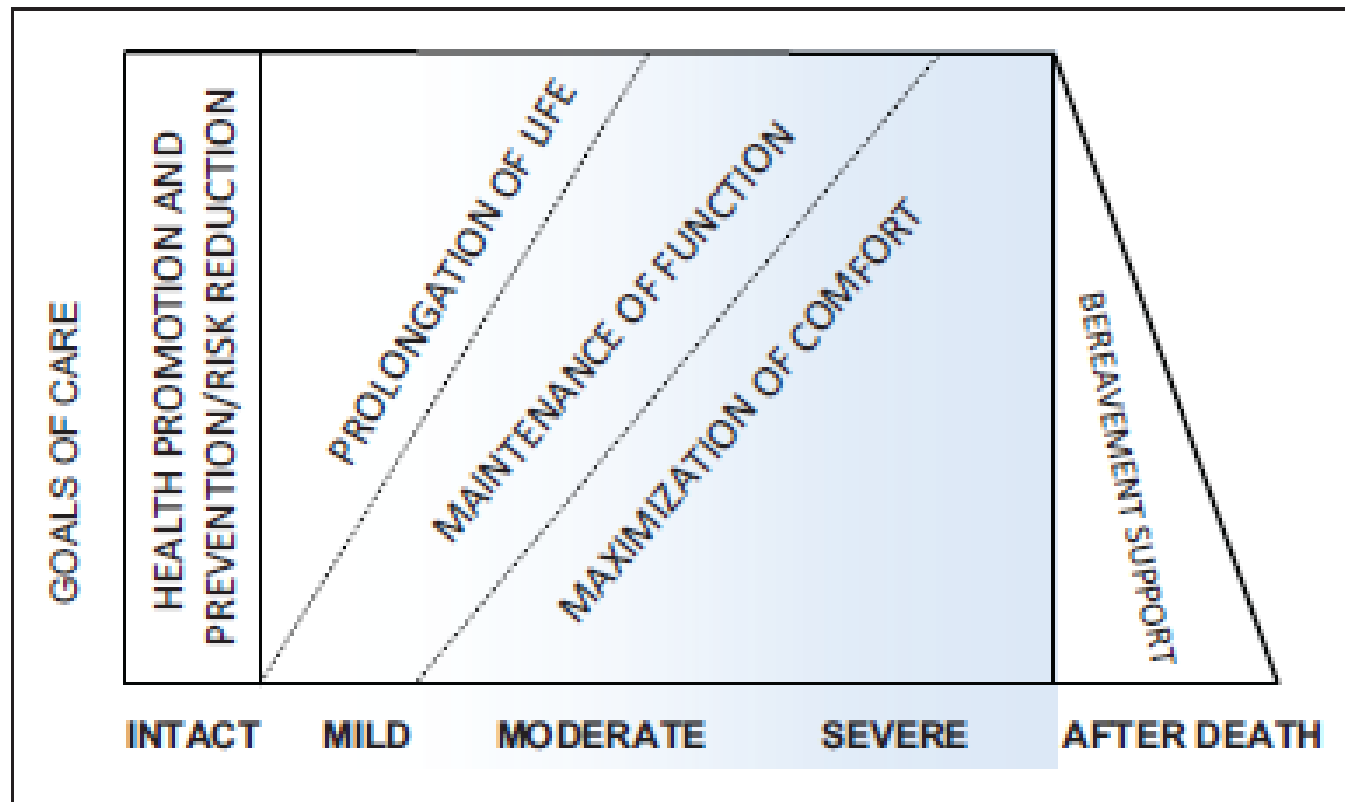
*The goal of palliative care is achievement of the best **quality of life** for patients and their **families**.”*

World Health Organization, 1990

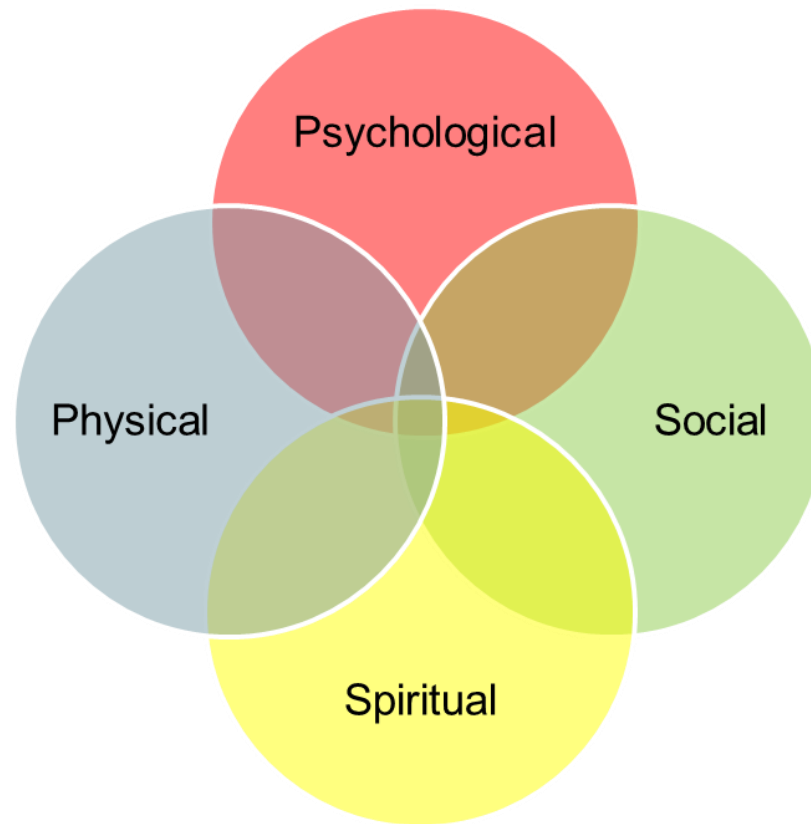
The dementia WE statements

“We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live”

EAPC White Paper on Palliative Care in Dementia



Palliative care is holistic care

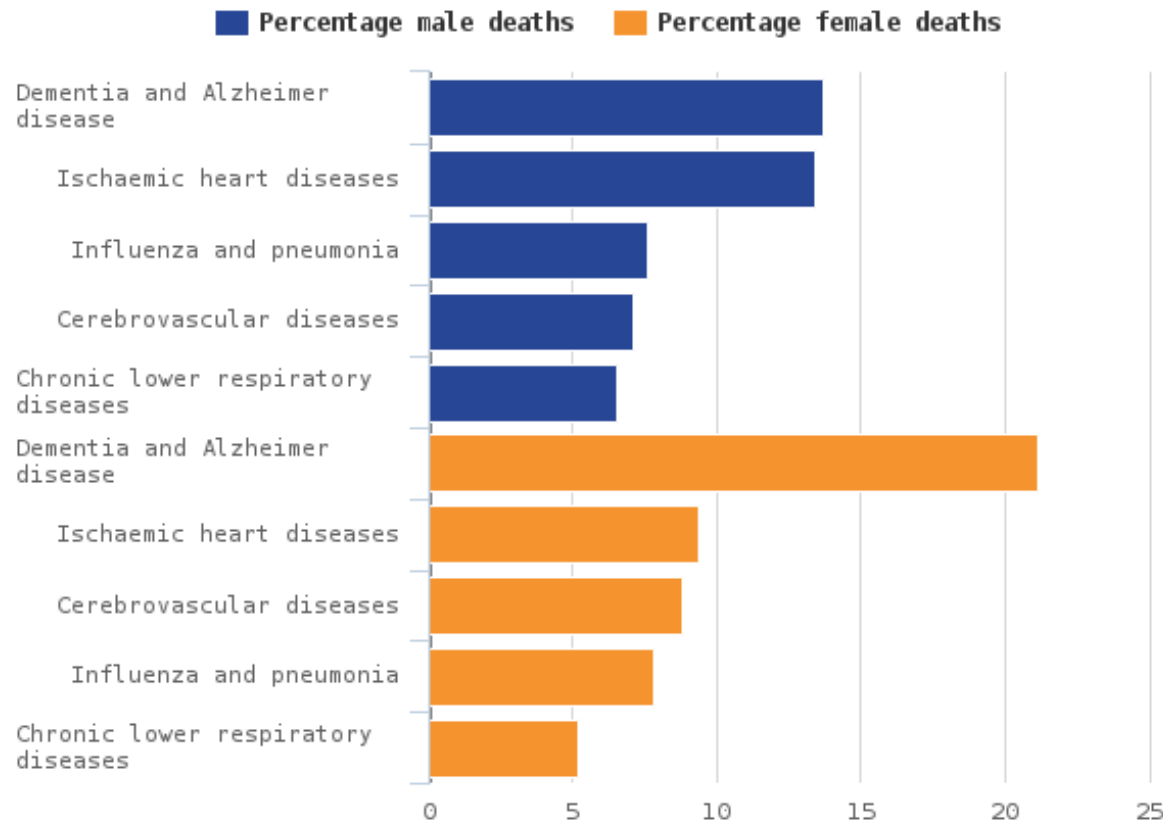


Palliare



Why is palliative care important for our society?

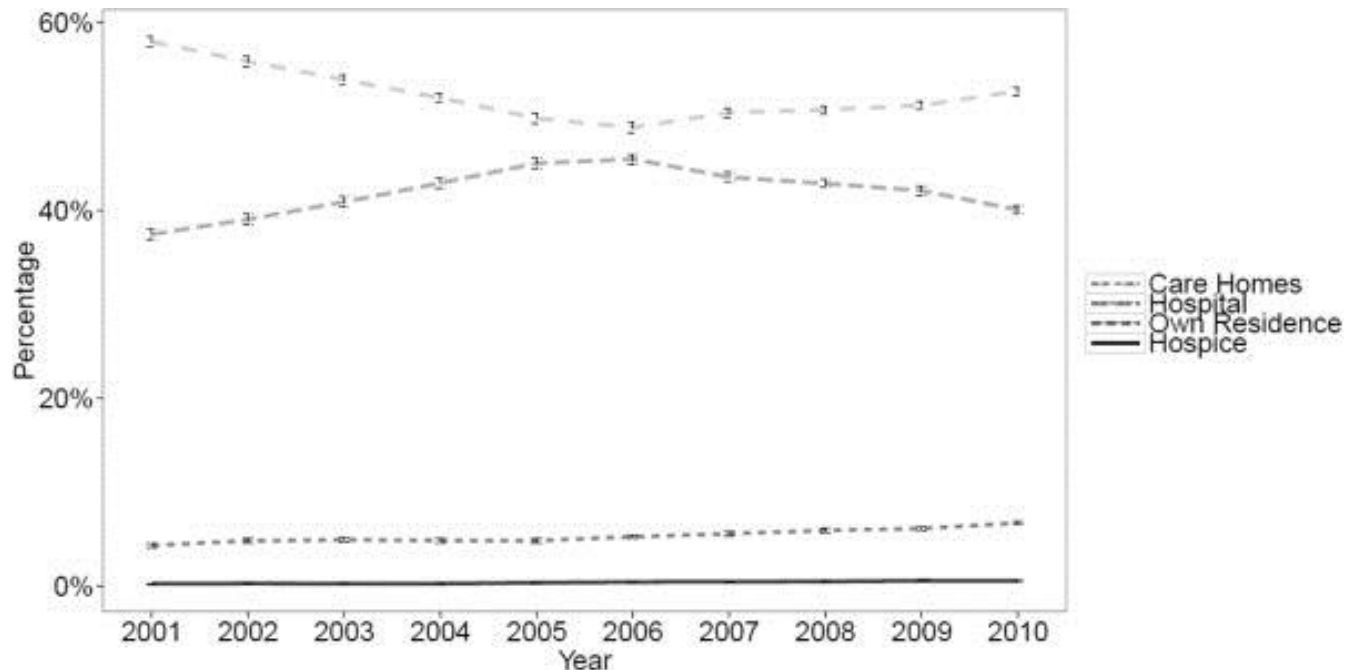
Dementia and Alzheimer's disease-leading cause of death



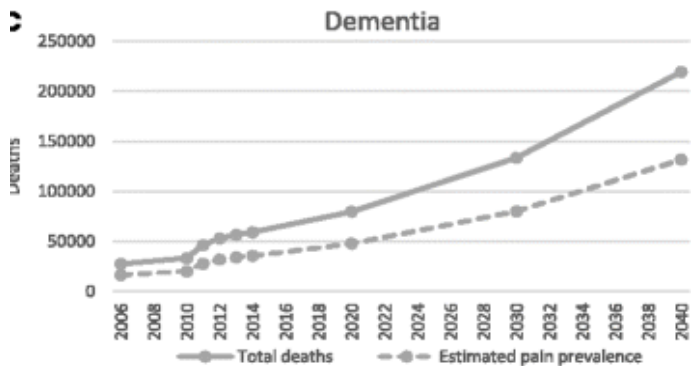
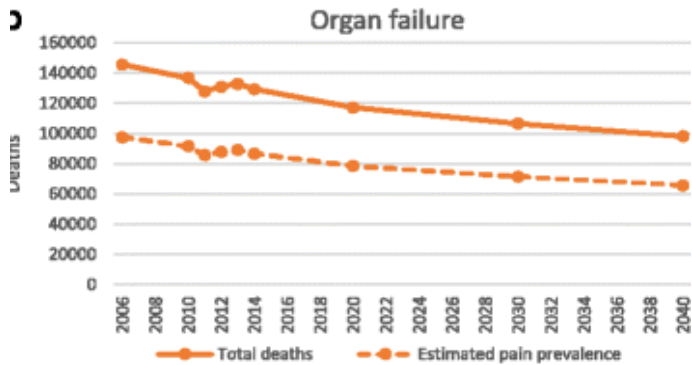
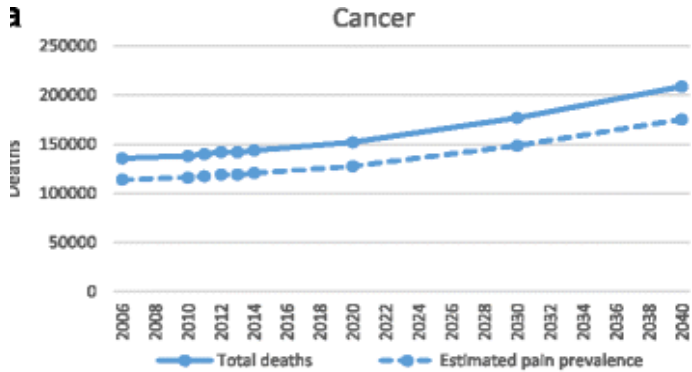
- Men and women over 80 (ONS Deaths Registered in England and Wales 2015)
- 30% of people over 60 years will die with dementia (Brayne et al. 2006)

Where do people with dementia die?

Reversal of the trend to towards death in hospital for care home residents



Deaths due to dementia will increase



Etkind et al. 2017

Why is palliative care important for individuals?

- We all want a good death!
- People may want to express their choices or wishes for their care at the end-of-life
- Plans are made too late or not at all
- In some cases symptoms such as pain and agitation are not managed well

Because you matter

*“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but **also to live until you die.**”*

Dame Cicely Saunders



Are their specific challenges for palliative care in dementia?

- Not recognised as a terminal illness
- Many losses occur *early...*
 - Personality and relationships
 - Personhood
 - Autonomy
 - Capacity
- Palliative care issues can occur at any time
- Equity of access and service provision
- Uncertainty and unpredictability

What can a palliative care approach offer?

...AND HOW CAN WE DELIVER THIS?

Advance care planning

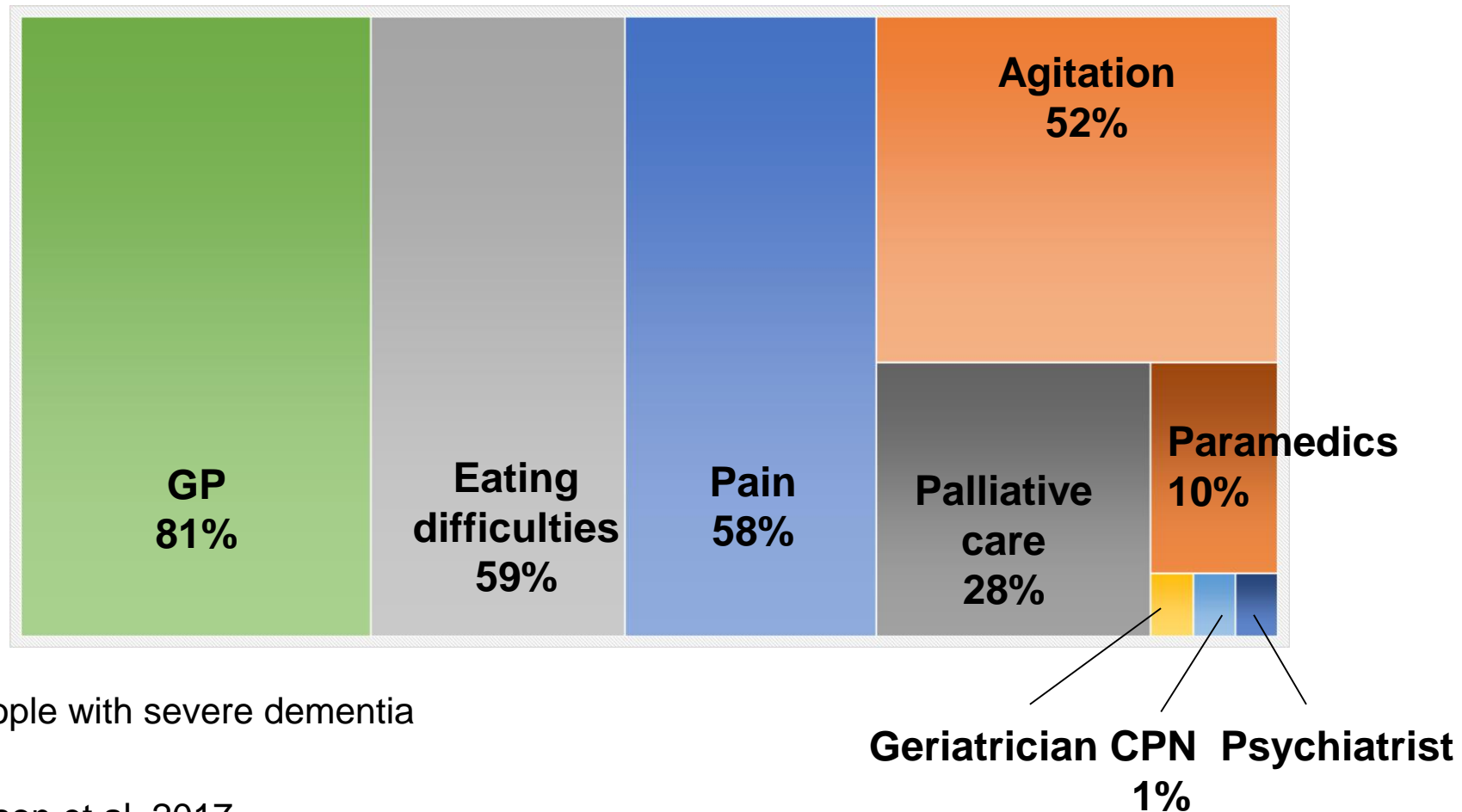


Work in care homes

- Gold Standards Framework
- Six steps to success
- My Home Life
- Namaste Care



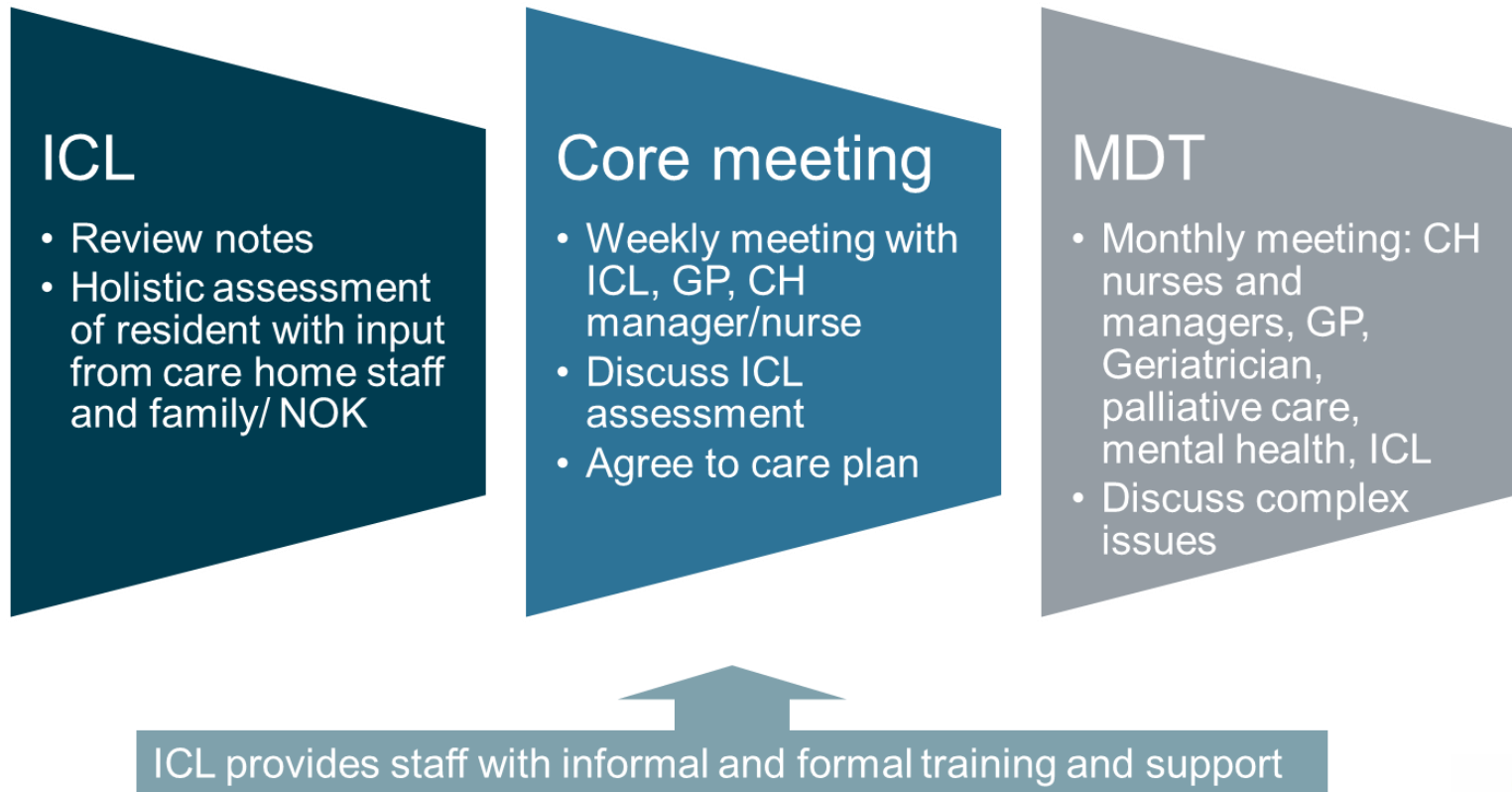
Why is more support needed?



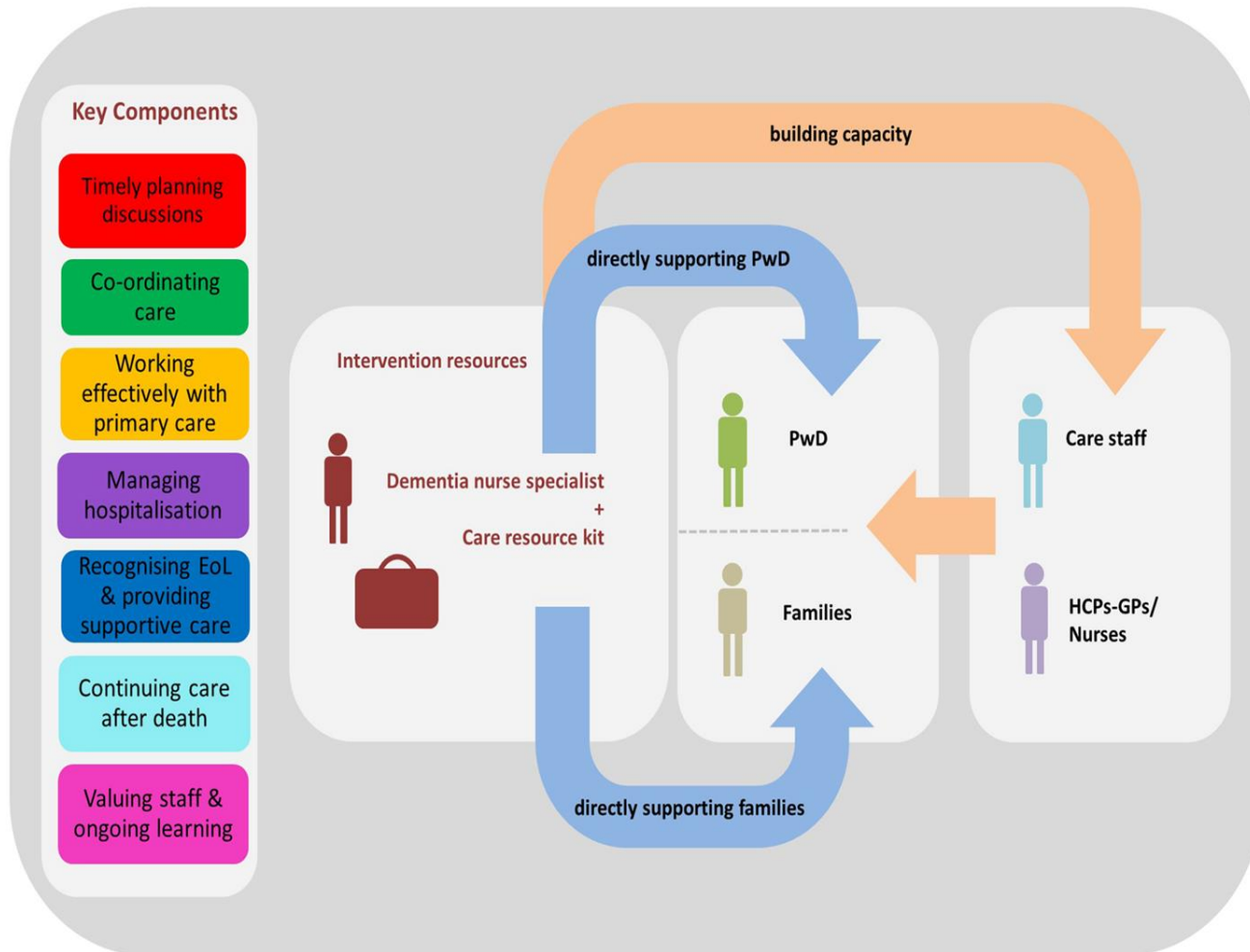
85 people with severe dementia

Sampson et al. 2017

Compassion Programme-care leader

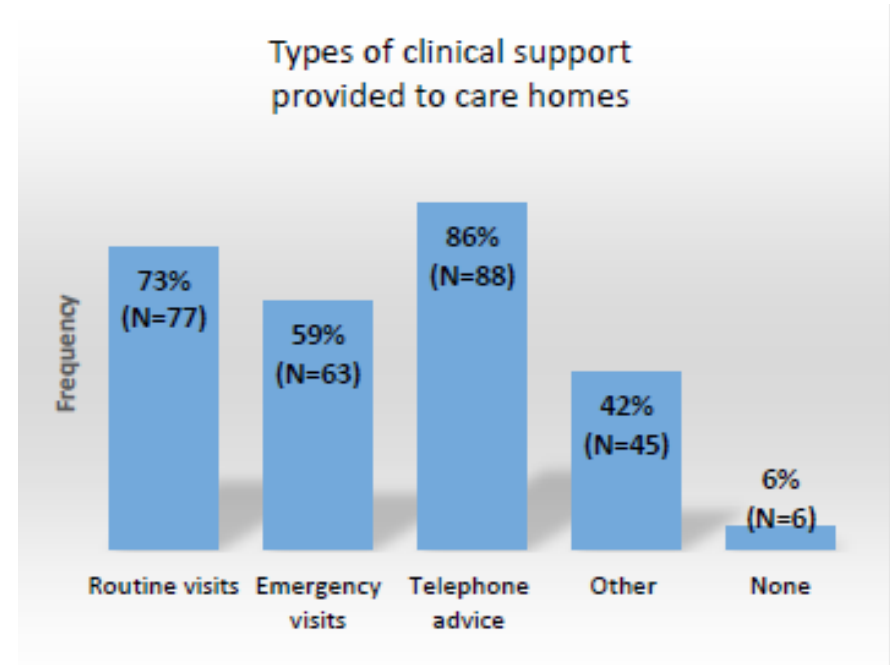


SEED programme-primary care



Hospice outreach

- Growing model
 - 2009-9 services
 - 2014-15 services
 - 2017-73 services
- Recent initiatives largely
 - nurse-led
 - driven mainly by charity and hospice sector (Amador et al. 2016)
- Commissioned funding key
- Lack of standardised data and KPIs (Public Health England, & Hospice UK 2017)



Summary

- We need to talk about dying-it matters!
- We know what to expect in the future
- Current care models do not support needs or changing demographics
- Hospice-standard care should be the vision for people with dementia
- Models are developing but need stronger evaluation and commissioning

Thank you



<http://www.ucl.ac.uk/mcpcrd/research/dementia>

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