Hospice UK
Real world
advance care planning
and living with dementia

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2016: 597,000 deaths in UK
450,000 (75%) were non sudden or predictable deaths who could benefit from expert EOLC
Transforming hospice care
A five-year strategy for the hospice movement
2017 to 2022

“Hospice care in the UK is at a pivotal moment...
Radical change is needed.”

5 years, 4 goals, 1 big ambition…
to open up hospice care

Goal 1. Extend our reach and enable hospice quality care to be delivered in any setting

Goal 2. Tackle inequality and widen access to hospice care

Goal 3. Work with communities to build capacity and resilience to care for those at the end of life

Goal 4. Empower a strong, dynamic and responsive hospice sector

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# What does Hospice UK offer?

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Welcome to PopNAT - Hospice UK’s Population Based Needs Assessment Tool

Hospice UK’s PopNAT (Population-based needs assessment tool) has been created to support hospices, local decision makers and other service providers across health and social care to plan for the future, identify unmet need and to innovate services based on intelligence about the end of life and palliative care needs of the local population.

PopNAT supports:

• Understanding local demographics in relation to palliative and end of life care
• Assessing service reach
• Identifying local systems of care
• Taking action based on evidence

We intend that PopNAT will evolve over time, and thus we welcome feedback, suggestions and reports on how you have used the knowledge gained from the tool.

Please contact popnat@hospiceuk.org or use the feedback forms in the tool.

There are two ways into the tool:

1. To look at the population around a specific hospice care provider choose “Search by provider”
2. To look at the population by local NHS administrative geographies for each of the four UK nations choose “Search by area”
Hospice enabled dementia care

Dementia care is an increasingly important strategic consideration for palliative and end of life care providers, including hospices.

However, there is a degree of uncertainty about what such care could and should encompass.

To this end we have produced guidance for hospices, which seeks to assure them they have much to offer people living with dementia and their families.

Through working in partnership with their local community and care providers, hospices can ensure that the best of hospice care is extended to everyone affected by a diagnosis of dementia within their local community.

In addition to this resource we have now established the Dementia end of life care Community of Practice in conjunction with Dementia UK.

Hospice enabled dementia care – the first steps

A guide to help hospices establish care for people with dementia, their families and carers.
Research and outcomes

Hospice UK supports hospices to be research and outcomes active. A focus on research and outcomes enables good quality care to be provided, described, evaluated and shared.

Ireland and New Zealand
Research, outcomes, dementia, advance care planning, knowledge
Real world
advance care planning
and
living with dementia
Advance care planning in England and Wales (other brands are available.....)

An advance care plan may include:

| Advance Decision to Refuse Treatment: ADRT | Lasting Power of Attorney: Health And/or Finance | Advance statement: verbal or written expression of wishes | DNACPR, Treatment Escalation Plans etc
|-------------------------------------------|-------------------------------------------------|----------------------------------------------------------|----------------------------------------------------------
| Written expression of future decisions | Surrogate decision maker | | Preferred place of care or death
| | | | Wills
| | | | Living with, preparing and planning for dying

Best Interests process

Mental Capacity Act (2005) implemented 2007
Safeguarding Vulnerable Adults
Deprivation of Liberty
Care:
“the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something”

Environment:
“the surroundings or conditions in which a person, animal, or plant lives or operates”
Asklepion Temple of Healing: Kos
4th Century BC to 2nd Century AD

Hospital of the Innocents
(Florence) Ospedale degli Innocenti (1419)

Aqua Tower: Chicago
(Jeanne Gang: Studio Gang Architects)

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“person’s wishes about anticipated deterioration of their condition in the future and possible loss of capacity to make decisions and/or ability to communicate wishes to others as a consequence of their deterioration”

“social and iterative process of communication between patients, family members and their healthcare provider”

1. Knowing the person and belief in ‘doing the right thing’
2. Importance of Wills and EPA
3. Negotiating unexpected encounters

Russell S (2016) Advance care planning and living with dying

1. Influence of design and use of space in advance care planning conversations.
The physical environment is a critical component of a therapeutic setting for people with dementia

“It’s how you use the space. They’re very clever. You see, they tell people ‘We’re all going to the movies today!’ then put chairs in rows, like the movies, and give them treats, then turn on the movie”.

A well-designed supportive physical environment has been shown to foster positive behaviours, such as reduced agitation, increased social contact, and less dependence in conducting activities of daily living.


PERSON–ENVIRONMENT INTERACTION: the interrelationship between individual competence and environmental demand i.e.
- biological health
- sensory-perceptual capacity
- motor skills
- cognitive capacity
- ego strength


Shifting the emphasis from condition to experience encourages the culture change needed to create environments that allow the person with dementia to be an active participant in everyday life rather than a passive recipient of care.

‘Therapeutic landscapes, ‘where the physical and built environments, social conditions and human perceptions combine to produce an atmosphere which is conducive to healing’


‘Key environmental factors shown to affect EOL care were those that improved 1) social interaction, 2) positive distractions, 3) privacy, 4) personalization and creation of a home-like environment, and 5) the ambient environment’.


“maintaining a sense of social participation, community belonging and personal identity”


- Complex relationships between people, places and care
- Care and care relationships are located in, shaped by, and shape particular spaces and places


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Use evidence to influence individualised care.....


UK, 800,000 people live with dementia and 670,000 unpaid carers support them.

Research into issues surrounding dementia and the end of life from carers’ perspectives is limited.

- Palliative care needs to be specifically tailored in cases of dementia due to the potential length of end-of-life periods and carers’ need to navigate feelings of guilt and grief throughout this time.
- Tailoring should focus on individual situational needs and ensure that supports are not time-limited, either before or after care recipient death.
Remember me, who I am, was and will be
Remember me, what I did, do and can do
Remember me, in my future, present and past

Do not forget, I once wiped your tears and made you tea
Do not forget, you were once my responsibility
Do not forget, you grew up through me

Remember me, dementia is not all I am
Remember me, dementia made us me and we
Remember me, I am still me

To find out more about Hospice enabled dementia care visit: www.hospiceuk.org
Advance care planning is chaotic – embrace it, navigate it
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