



LOROS Annual Lecture

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A Good Death in Dementia

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A local hospice, caring for local people

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LOROS
Hospice Care for Leicester, Leicestershire & Rutland

Being there for *you*
and *your family*

helping families face dementia



Aims of this talk

Five parts to this presentation.

1. Overview of dying with and from dementia.
2. Early enquiries during my PhD.

Work in progress:

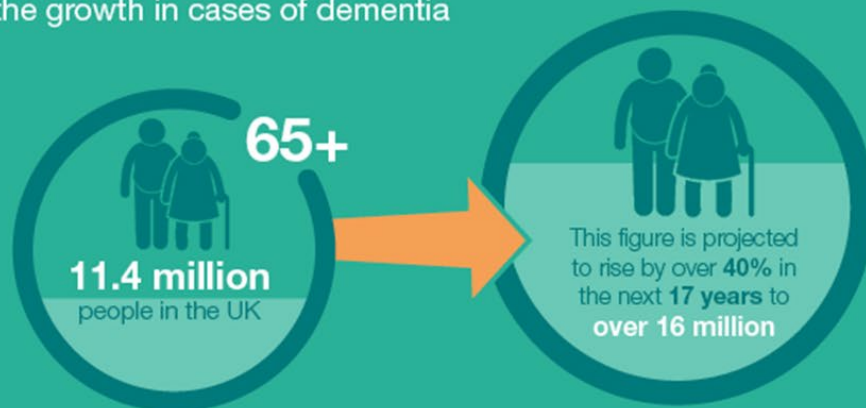
3. Collecting data from a range of studies.
4. An international comparison of a good death.

Post script

5. Covid-19

Age is the biggest risk factor for dementia

The ageing population is fuelling the growth in cases of dementia



By 2040

nearly 1 in 4 people in the UK (24.2%) will be aged 65 or over



1 in 688 people under 65 have dementia

1 in 14 people over 65 have dementia, and this rises to 1 in 6 for people over 80





What is dementia?

Dementia is an 'umbrella' term that includes all types of dementia and is caused by several diseases and conditions that affect the brain.

Dementia is a progressive condition with no current cure.

Typical symptoms are:

memory loss, disorientation, impairment of thinking and reasoning

problems with language, personality changes, behavioural and psychological symptoms, decline in ability to perform ADL's



Progressive deterioration

In addition...

Only 2/3^{rds} of people with dementia receive a formal diagnosis

Nearly half will have a mix of conditions in addition to their dementia

Half of those with dementia admitted to acute hospital die within 6 months

There are multiple challenges for professional carers but importantly for family carers who provide most care

Dementia does not come alone....

Comorbidity refers to the presence of more than one condition in an individual.

Multi morbidity is the co-occurrence of multiple chronic or acute diseases and medical conditions within an individual.

Frailty is a state that encompasses losses in physical, psychological or social domains.

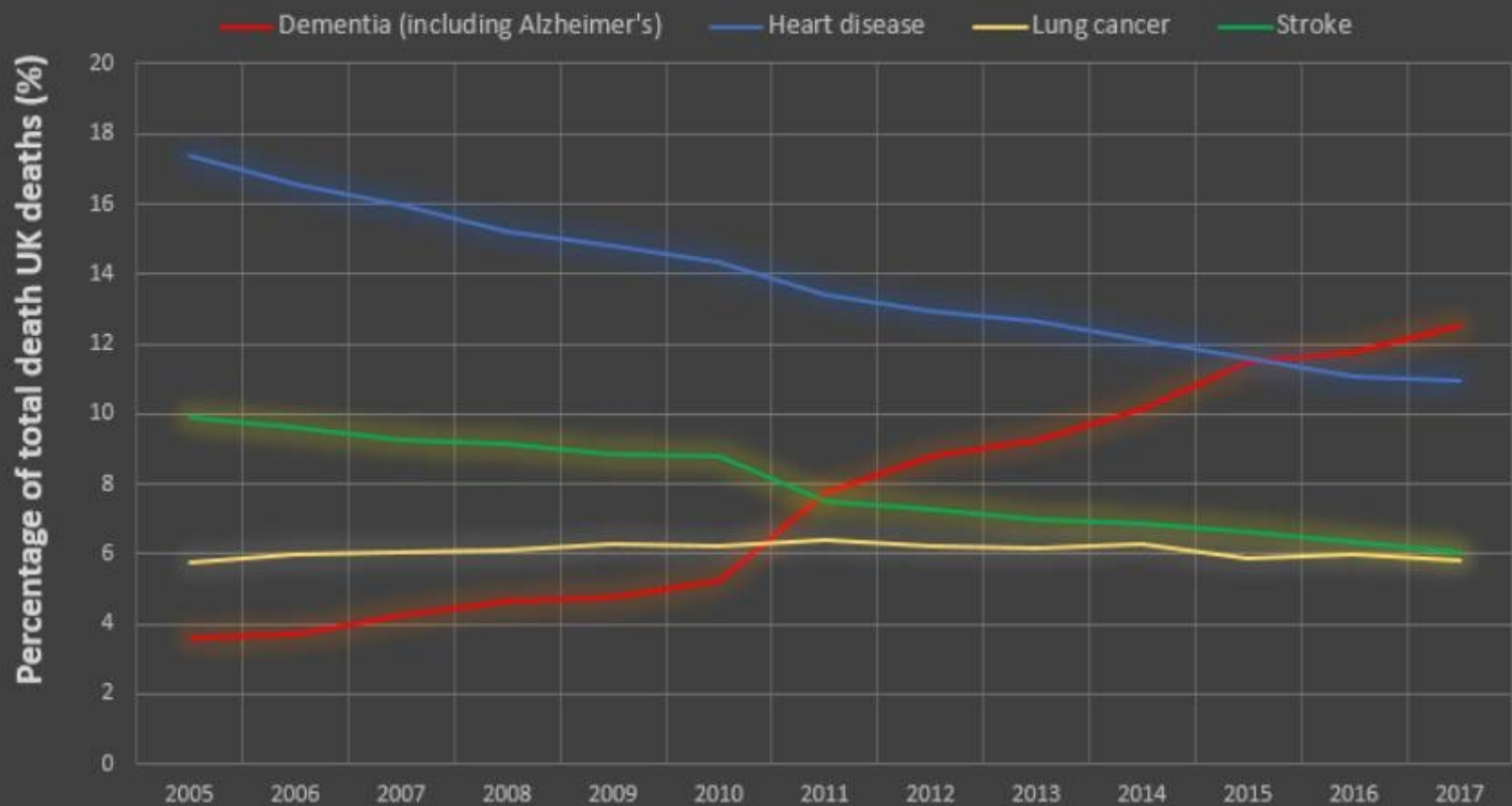
And to add.....

On average people with dementia have 4.6 chronic illnesses **in addition to their dementia.**

In addition, delirium, infections, falls, urinary and faecal incontinence, constipation and epilepsy occur more frequently in people with dementia.

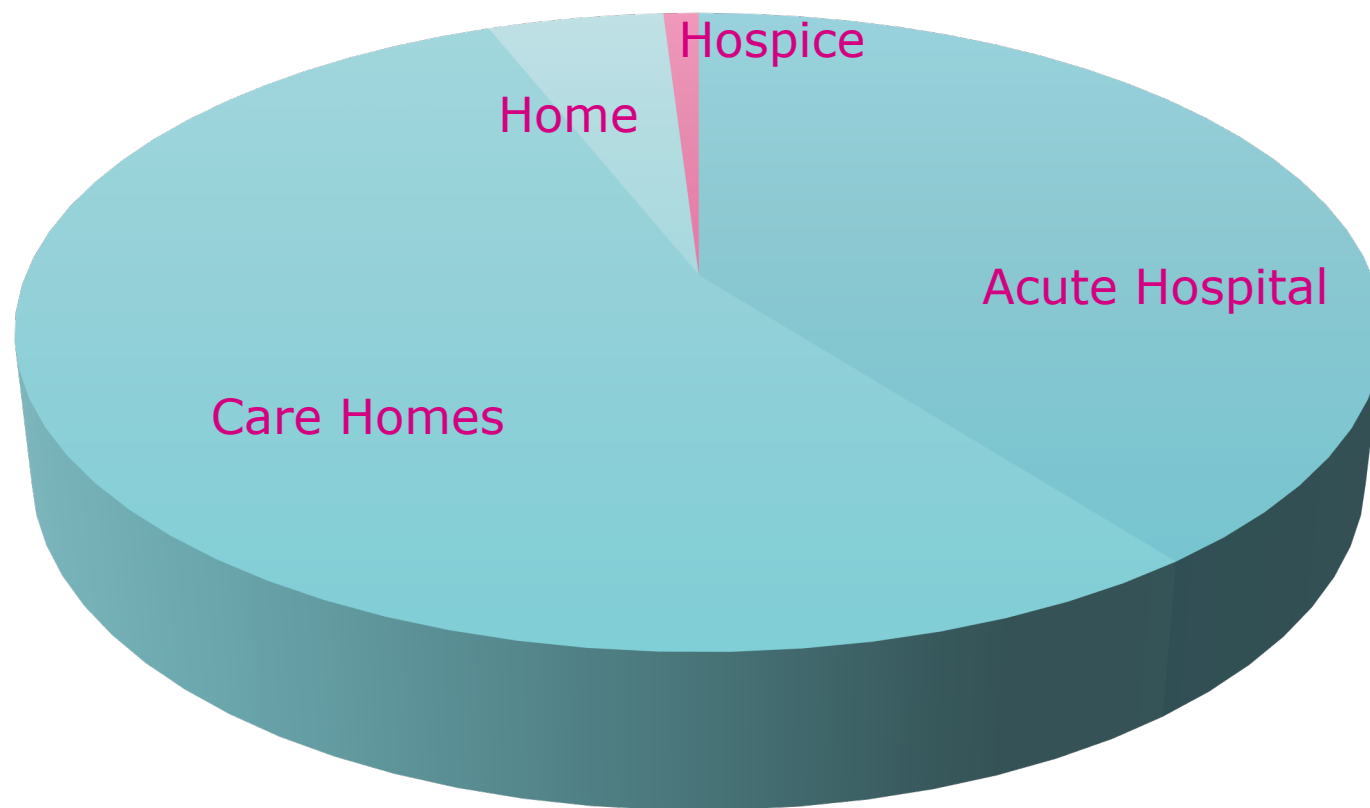
Over a third of people with dementia also have moderate or severe frailty. Over 45% of those with severe frailty was found in people with moderate dementia.

Top four causes of death in UK





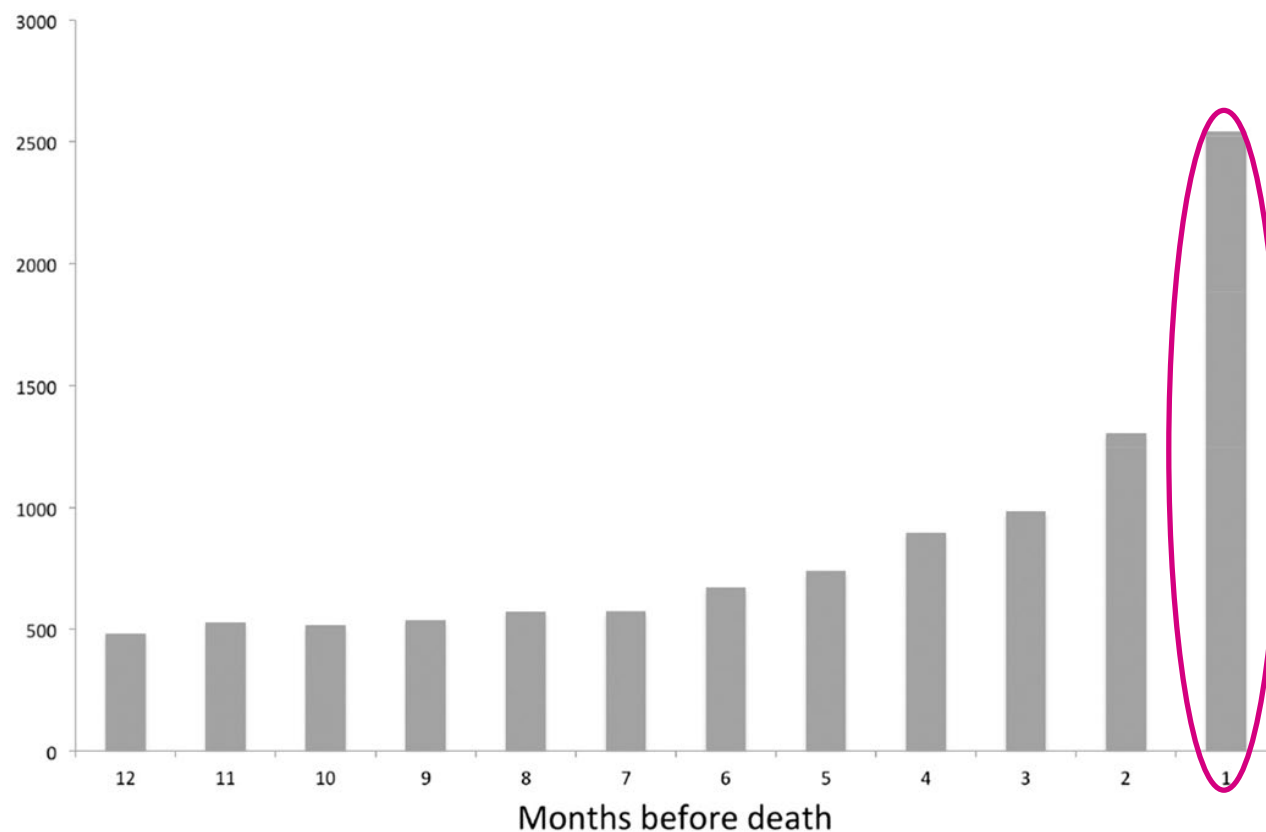
Where do people with dementia die?



We need to measure more than place of death in dementia



A&E attendance increases as a person with dementia gets closer to death



Attendance at A&E is still very common

Over 75% in the last year of life

Over 40% in the last month

Over 20% in the last week



The role of care homes in end-of-life care in dementia



460,000 beds available in care homes of which 1/3 require end-of-life care.
75% plus of residents at any one time will have dementia.
Less than 50% of care home beds are registered to provide nursing care.



One in three people who die in a care home are a temporary resident.



Deaths in care homes increased from 80,000 to over 120,000 in the last 6 years.
70% of care home residents die in a care home.



Access to care for people with dementia and complex needs

Poorer access to equivalent care for similar health conditions and experiences.

Miss appointments and follow-up.

Difficulty in recognising change and illness.

Dementia over shadows.

Visual and hearing impairment may go unnoticed.

Care is heavily dependent upon the input of a family carer or supporter who knows the person well.



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PhD



Consultant Nurse role and opportunity

Clinical practice

Policy

Advance Care Planning in dementia

Understanding a persons wishes and preferences

Carer knowledge and influence

PhD – phase one ⁽¹⁾

Nominal Groups to explore whether people with dementia and their carers were able to generate ideas about the choices they may wish to make for end of life care.

3 nominal groups:

- x1 people with dementia

- x1 carers of people with dementia

- x1 people with dementia and their carer



PhD – phase one (2)

Wishes and preferences of the people with dementia for their future care
(Good death?)

- Maintaining family links
- Independence
- Person centred care
- To remain in touch with the world
- A comfortable environment
- Pleasurable occupation
- Dignity
- To feel safe
- Not to be a burden
- A choice in place of care

PhD – phase one ⁽³⁾

Carer group - No unnecessary prolonging of life

People with dementia group - Maintaining family links

Dyad group - No unnecessary prolonging of life

PhD – phase one (4)

Conclusions

Such discussions did not cause undue distress

Divergence of views

When present, carers influenced the person with dementia

People with dementia found it difficult to consider their future selves and end of life care issues

Implications

Direct approach is OK

Carers' ability to predict the preferences of the person with dementia

Guidance for practice



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Cross-cultural Conceptualization of a Good End of Life with Dementia: A Meta-qualitative study

The purpose of this study is to assess cross-cultural commonalities and any differences in concepts of a good end of life with dementia.



Miyashita, M; Van der Steen, J; Sampson, E.L; Kaasalainen, S; Davies, N; Harrison Dening, K; Moore, K., Bolt, S;



Methods

Focus groups and interviews with researchers of studies on end of life with dementia.

Examined the literature to find more researchers of studies from across the globe, not just western Europe.

Researchers were interviewed sessions in spring 2019 to discuss what is important at the end of life for people with dementia based on their research findings.

Arising themes were analysed.



Early findings ⁽¹⁾

Three main but basic requirements included:

Pain and Symptom Control
Good Basic Care and
A Place Like Home.

3



Spiritual Existential

Psychosocial

Physical

Satisfaction with life

Remaining connected

Respected as a person

Person with dementia

Relationships

Family/Carers

Preserved identity

Not being a burden

Personal preferences

A homely environment

Symptom management

Care

Spiritual Existential

Psychosocial

Physical

Early findings ⁽²⁾

A wide range of themes are relevant to a good end of life with dementia regardless of the cultural context.

Some indicate aspects that are particularly **challenging to achieve** for people with dementia.

However, differences in importance of the themes may relate to the extent that they are modifiable such as through **improving particular aspects of care**, in addition to cultural values.



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In search of a good death: What does a good death in dementia look like?

A qualitative study comparing views of people with dementia in Brazil & UK

We know a little about this in other diseases, such as cancer.

Raising this question in people with dementia is lacking.

Currently views on end-of-life in dementia are largely based on professional and clinical opinions.

Tends to focus on clinical symptom management such as pain reduction.



In search of a good death: What does a good death in dementia look like?

A qualitative study comparing views of people with dementia in Brazil & UK

Better understand what a 'good death' is for people with a diagnosis of dementia.

Consider the views of people with dementia from diverse backgrounds and their access to different types of services.

Early findings

8 interviews achieved in UK

5 in Brazil (Not yet transcribed)

Need for continued control over their lives but a realisation that this may not be possible as the dementia progresses.

Considerations they have given to how control might be achieved.

Little discussion from professionals on what they might need to think about.

Little faith in the 'system' to meet their needs as the disease progresses.

Early findings

[husband] will give me the best care that anyone can give me and he will look after me and I am 100% confident of that. If I go into a hospice or hospital they don't know me from anybody else...they don't know what I like, they don't know what I dislike, they don't know any part of me really so I'm a stranger to them and I just don't think I'd get anywhere near that same sort of care.

I've not got a fear of dying.
What I've got a fear of is
either dying in pain or living a
life where I am not me...like
that empty shell...

... and they don't tell you what
that is and they don't tell you
what they're gonna do about it.

oh ... it was like a sense of ... I
don't really want to deal with
this ... off you go ...

Why is this important?

There is still much to do to improve dementia care per se.

In the UK the total cost of care for people with dementia is currently £34.7billion. By 2040 this is predicted to rise to £94.1billion.

There is little consideration of the needs of people dying with dementia in UK health care policies, which leads to inequity in care.

Emergency dementia admissions to hospitals up 35% in five years

NHS data for England shows reality of social care system, says Alzheimer's Society



The number of people with dementia being an emergency has risen by more than a third in five years with a lack of social care blamed for the increase

NHS data showed that hospitals in England saw a 35% increase in emergency admissions of people with dementia in 2017/18 compared with 2013/14

'My mum spent most of her last year in hospital'



MailOnline

Hospitals treat 1,000 dementia patients a day because basic social care is so poor they are forced to turn to casualty wards for help

- Experts say patients end up in hospital 'in crisis' due to failings in social care
- Were 344,522 emergency admissions involving dementia patients in 2017/18

up from 257,559 cases in 2013/14
change.org/dementiacare

TH FOR THE DAILY MAIL
August 2019

Care Quality Commission The independent regulator of health and social care in England

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Variation in the quality of care means people living with dementia risk receiving poor care

Published: 13 October 2014

Categories: Media

Read the report

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[Cracks in the pathway](#)

A major review of dementia care by the Care Quality Commission



DementiaUK
Helping families face dementia

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‘Lifeboat ethics’



Triage
Rationing
Removal of ‘non-essential’ services
Intensification of poor quality care



BMA

All patients should be given compassionate and dedicated medical care including symptom management and, where patients are dying, the best available end-of-life care. Nevertheless, it is legal and ethical to prioritise treatment among patients. This applies where there are more patients with needs than available resources can meet.

Other relevant factors include:

severity of acute illness

presence and severity of co-morbidity

frailty or, where clinically relevant, age.

BMA advise the application of the Clinical Frailty Scale (CFS) to assess an individuals suitability for intervention (ventilation).

<https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-faqs-about-ethics>

Clinical Frailty Scale*



1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



3 Managing Well – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



5 Mildly Frail – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6 Moderately Frail – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



7 Severely Frail – Completely dependent for **personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. Terminally Ill - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia.

Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.

2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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DementiaUK
Helping families face dementia



NICE

In April, NICE linked to ethical guidance from the British Medical Association, the Royal College of Physicians and the General Medical Council to support healthcare professionals with decision making. NICE also linked to new government guidance on managing exposure to COVID-19 in hospital settings.

However, several leading dementia organisations and clinicians felt NICE guidance had the potential to disadvantage people with dementia as **even mild symptoms may inflate the CFS score**. This would lead to the possible outcome that people with dementia would be disadvantaged when it came to a referral for critical care.

When challenged NICE responded by saying that the CFS should only be used as *part* of a holistic assessment – even more difficult to imagine a fully considered triage and assessment given the pressure on health systems and also the speed at which decisions are required. This requires the family affected by dementia to have absolute confidence in such guidance and its equitable application.



Care Quality Commission (CQC) commentary

Concerns emerged that DNACPR decisions had been issued for groups of care home residents.

Unprecedented pressures led to “do not attempt resuscitation” (DNACPR) decisions being made.

Blanket decisions.

DNACPRs and advance care plans.

Journal of Dementia Care (2021)



Discussion & questions



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