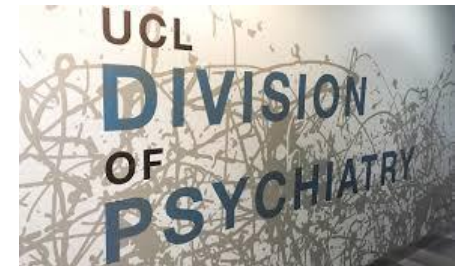


# Palliative care for people with dementia

(and others we may look after too.....)



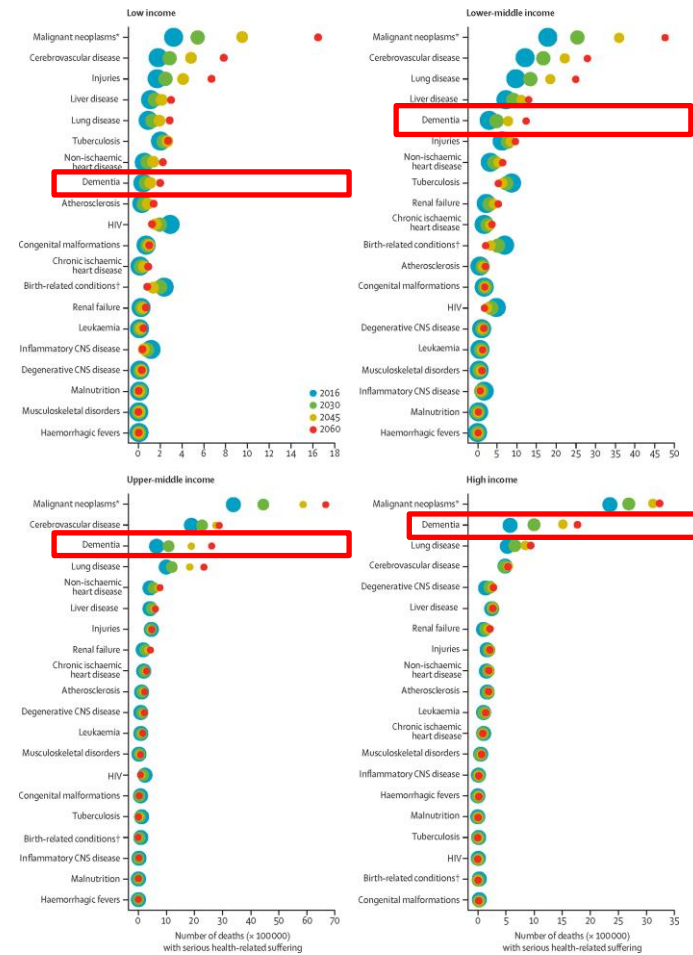
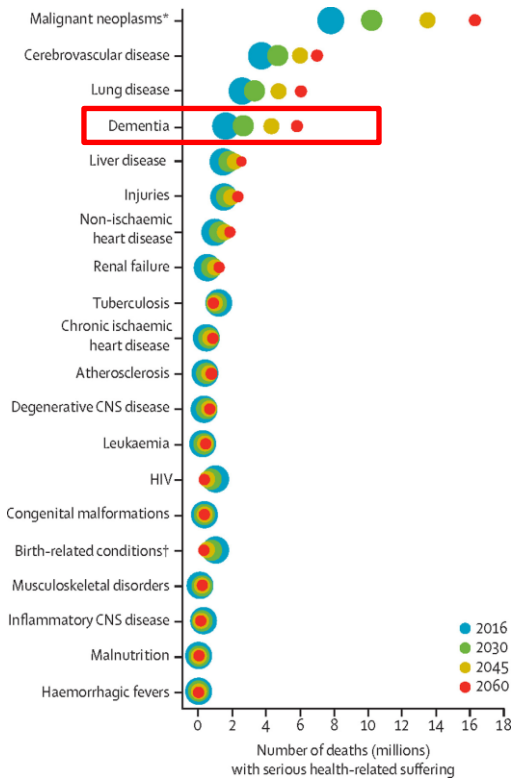
Professor Liz Sampson,  
Division of Psychiatry, UCL, London  
Liaison Psychiatry, North Middlesex University Hospital



# Overview

- Demographics of dying with dementia
- Critical overview of ACP
- The role of memory clinics and non specialist services

# Dying with dementia as a global issue



Sleeman et al. 2019

# 47,744 PEOPLE ARE CURRENTLY LIVING WITH DEMENTIA IN IRELAND

30,359  
WOMEN



17,385  
MEN

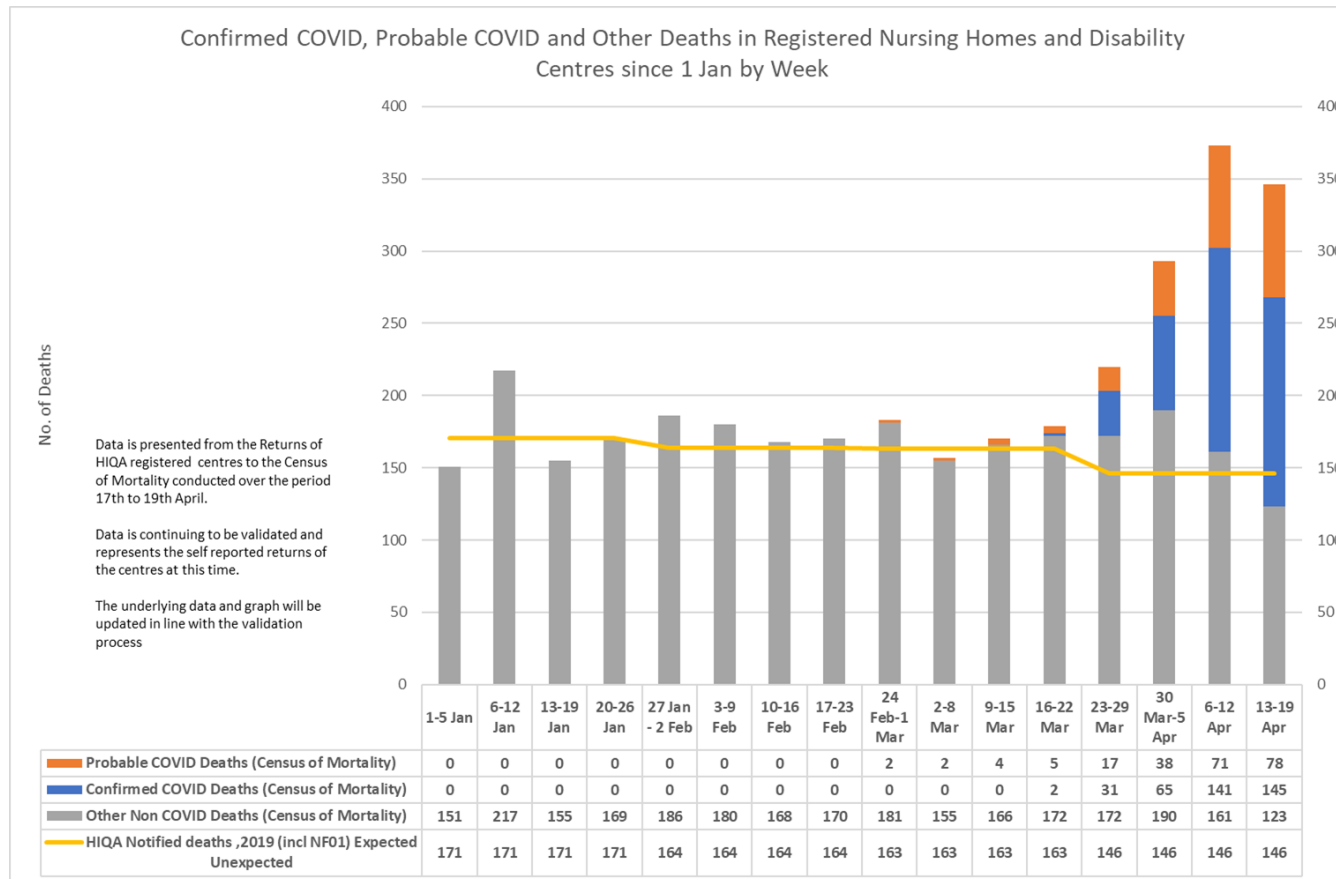


Cahill, S. & Pierce, M (2013) The Prevalence of Dementia in Ireland. Genio Dementia Learning Event

## Deaths of people with dementia in Ireland

- 4,200 each year
- 2,310 in residential care settings
- 1,680 in acute hospitals
- 210 in their own homes (IHF-2015)
- Will treble by 2045 (Pierce 2014)

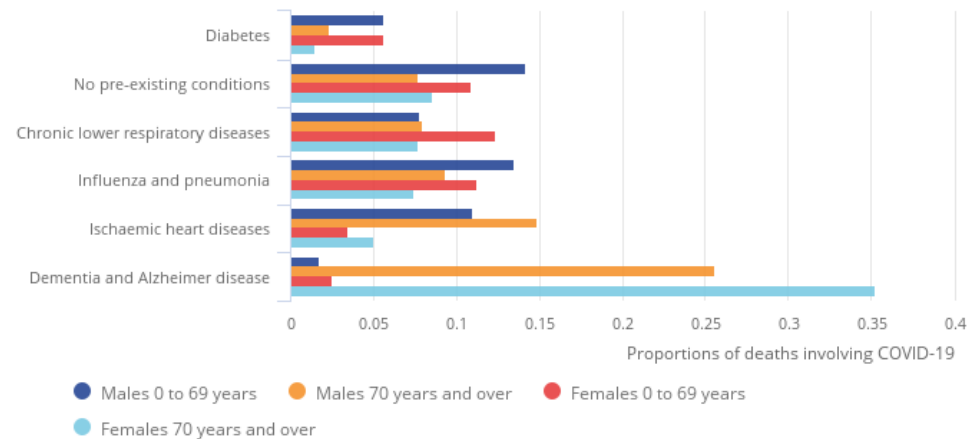
# Vulnerable people in vulnerable settings



# Mental health problems and dementia

## Pre-existing health conditions in deaths involving COVID-19: March-June 2020

Proportion of deaths involving COVID-19 by main pre-existing condition, sex and age, England and Wales, occurring in March to June 2020



Source: Office for National Statistics – Deaths involving COVID-19

### Articles

#### Prevalence, management, and outcomes of SARS-CoV-2 infections in older people and those with dementia in mental health wards in London, UK: a retrospective observational study

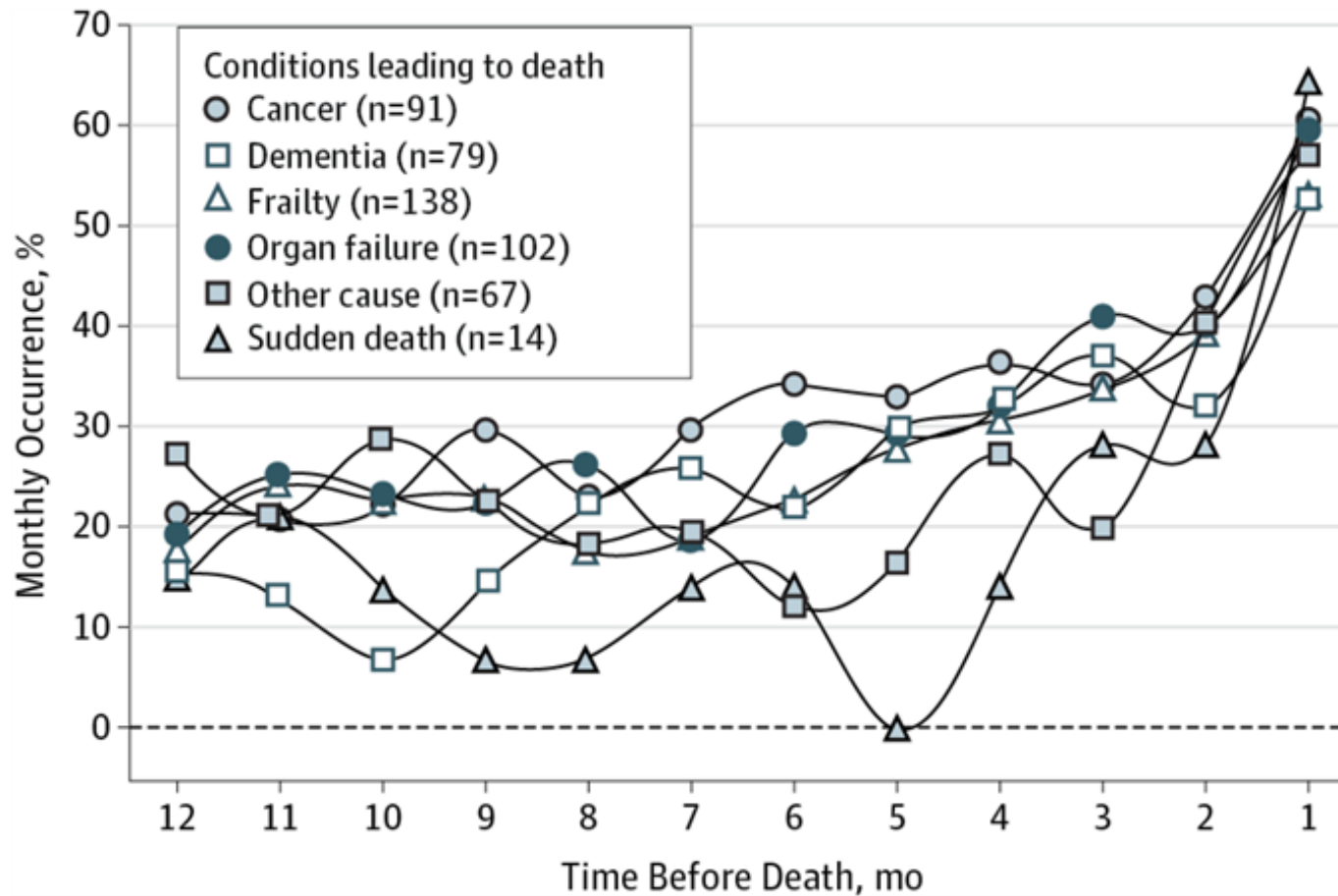
Gill Livingston, Hossein Rostampour, Paul Gallagher, Chris Kalafatis, Abhishek Shastri, Lauren Huzzey, Kathy Liu, Andrew Sommerlad, Louise Marston

- 38% contracted COVID-19 (n=344)
- Higher proportion died

# The mortality of dementia

- 1990-2016 number of deaths due to dementia increased 148% (140–157)
- Dementia fifth-largest cause of death (2.4 million [95% UI 2.1–2.8] deaths) after ischaemic heart disease, chronic obstructive pulmonary disease, intracerebral haemorrhage, and ischaemic stroke (2016)
- Deaths due to dementia accounted for 4.4% (95% UI 3.8–5.1) of total deaths but 8.6% (7.4–10.1) of deaths in over 70s (2.2 million [1.9–2.6] deaths)
- More women than men died from dementia in 2016 (1.5 million, 95% UI 1.3–1.8 vs 0.8 million, 0.7–1.0).
- In the UK 30% of those over the age of 60 will die with dementia (Brayne et al 2006)

# Symptoms as death approaches





# 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

# Why is dementia different?

Not recognised  
as a terminal  
illness

Structural  
barriers to care  
provision

Expectations of  
families

Many losses  
occur *before*  
death

Personality

Personhood

Agency

Autonomy

Capacity

# Impact on families, friends and staff



*“How people die remains  
in the memory of those  
who live on”*

Dame Cicely Saunders

- Anticipatory, pre-bereavement and complicated grief (Moore et al. 2017)
- “Aggressive” care for the person with dementia associated with worse bereavement experiences
- Decisional conflict = worse care mental health and grief outcomes (Brazil 2017)

# Prognosis

Notoriously difficult and unreliable

Combined prognostication index and physician estimates most accurate  
(van der Steen 2011)

Good at telling who won't die (!)

Does knowing the prognosis...?

- Change management ?
- Improve outcomes i.e. comfort
- Help families and carers

Better approaches

- Treatment escalation and ceiling of care plans
- Acknowledging and holding uncertainty
- Needs-based

# Advance care planning

*“...a **process** of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individuals agreement, this **discussion** should be documented, **regularly reviewed**, and **communicated** to key persons involved in their care”*

*Advance care planning; A guide for health and social care staff (2007)*

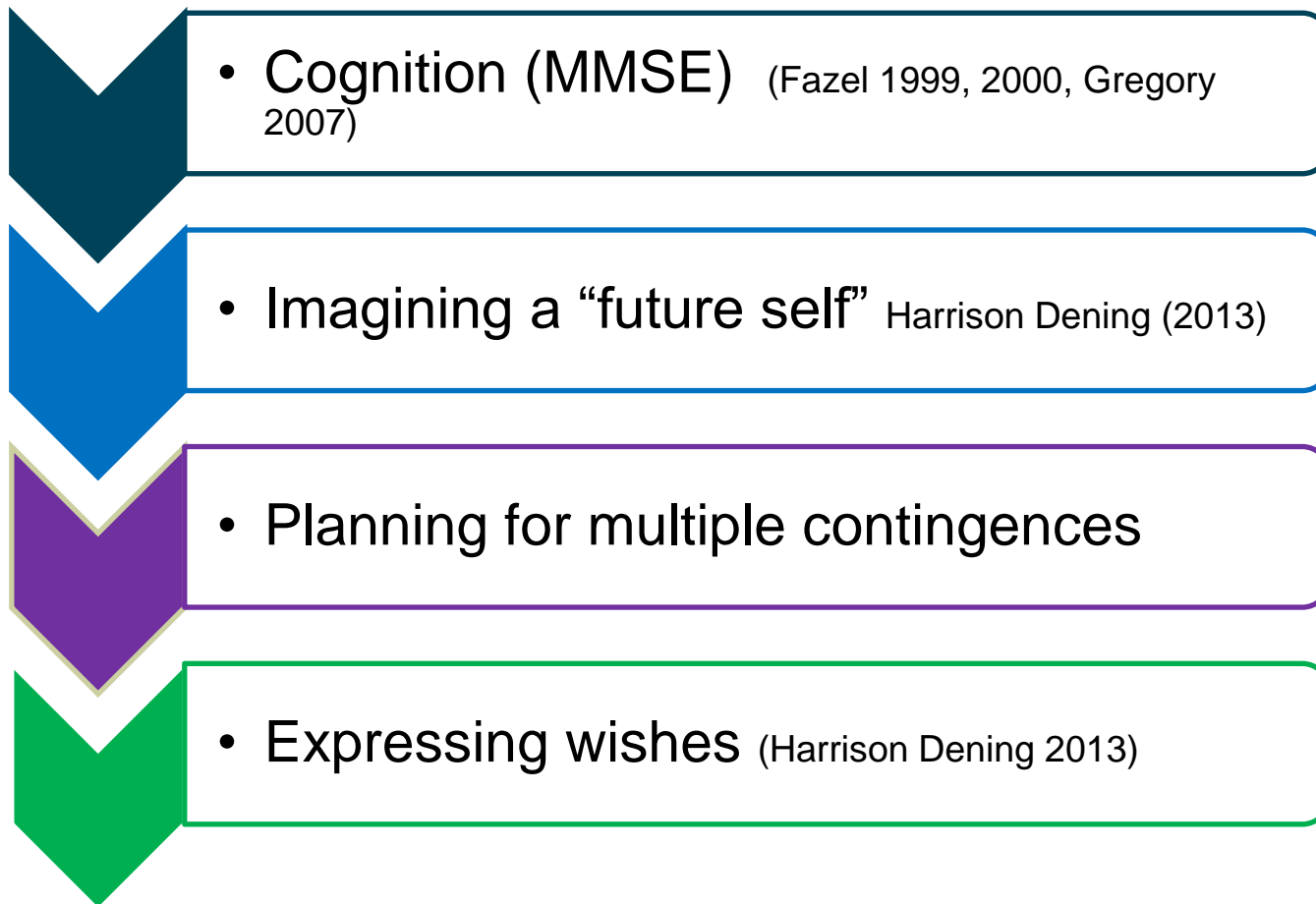
# Is advance care planning effective?

- Improves outcomes In other life-limiting conditions
  - Death in preferred place of care (Detering 2010, Silveira 2010)
  - Reduces ‘aggressive’ interventions near death (Detering 2010, Wright 2008)
  - Reduces costs (Zhang 2009)
- Improves outcomes for families
  - reducing anxiety, depression and post-traumatic stress disorder (Detering 2010, Wright 2008)
- Positively impacts the quality of end-of-life care (Brinkman-Stoppelenburg 2014)

# The evidence base for advance care planning in dementia

- Less robust (Robinson 2013)
- Strong association between having a written advance directive and quality of dying
- Where wishes are written, relatives report lower levels of emotional distress at the end of life (Vandervoort 2014) and less decisional uncertainty (Brazil et al 2018)
- Significantly improved
  - documentation
  - identification of patients' wishes regarding common life-sustaining treatments
  - concordance between prior wishes and treatments (Morrison 2005)

# Capacity-a dynamic process





## Response shift

“A person’s perceived quality of life in the context of illness and a re-calibration to their new health state” (Schwartz, 2010)

- Re-calibration, reprioritization and reconceptualization of “what it means *to be alright*” (Harrison Denning 2013)
- A changing frame of reference
- Also occurs in families, carers and staff (Perren 2006)
- Under-researched in dementia

# Systemic challenges

- Implementation
- A “false promise
- Varied legal frameworks
- Confusing array of forms of documentation
  - Lasting Power of Attorney
  - Advance statements
  - Person centred documentation



# Ownership

- Professional responsibility
- Initiating the process
- Reviewing the plan
- Ensuring the plan is enacted (Robinson 2013)



# Politics

Cookie Policy | Feedback | Like | 2m | Follow @MailOnline | DailyMail | Tuesday, Sep 16th 2020

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The fashion show must go on: Models

'Bow down to your imperial master

'We'll give you more powers AND more

POLL OF POLLS

51% 46%

Are all those neck-and-neck Scottish

1 in million

### Do you want us to let you die? Question nurses on home visits are told to ask elderly patients they have just met

- Patients asked via form if they would agree to a 'do not resuscitate order'
- Elderly are being given questionnaires as part of an NHS England scheme
- Experts fear patients will feel pressured into giving consent to avoid trouble
- Forms sent to GP practices in June, with district nurses visiting patients
- They are targeting the over-75s and patients with long-term conditions

By SOPHIE BORLAND, HEALTH CORRESPONDENT  
CREATED: 23:09, 19 August 2014

Share
 




**532** shares
 **586** View comments

## Fury at 'do not resuscitate' notices given to Covid patients with learning disabilities

Vulnerable people have encountered 'shocking discrimination' during pandemic, says Mencap charity

- [Coronavirus - latest updates](#)
- [See all our coronavirus coverage](#)

AT  
99,008



▲ 'People with learning disabilities already get a raw deal from the health services.' Photograph: Nathan Stirk/Getty Images

People with learning disabilities have been given do not resuscitate orders during the second wave of the pandemic, in spite of widespread

# Recent evidence on advance care planning

## For

- Policy push
- It seems like a good idea (!)
- It gives people choice and control
- It gives a sense of relief and less worry (Poppe 2013)
- Reduces family carer uncertainty in decision-making and improves perceptions of quality of care (Brazil et al. 2017)
- In other disease i.e. cancer it influences preferred place of death (Deterring 2011)

## Against

- Lose capacity relatively early (Harrison Dening 2016)
- False promise-can't deliver
- Proxies find it stressful (Fetherstonhaugh 2017)
- Proxies are not good at predicting (Harrison Dening 2017)
- Professional ownership (Robinson 2015)
- Response shift (Jongsma 2016)

# Where to begin?



# Is there a role for memory clinics ?

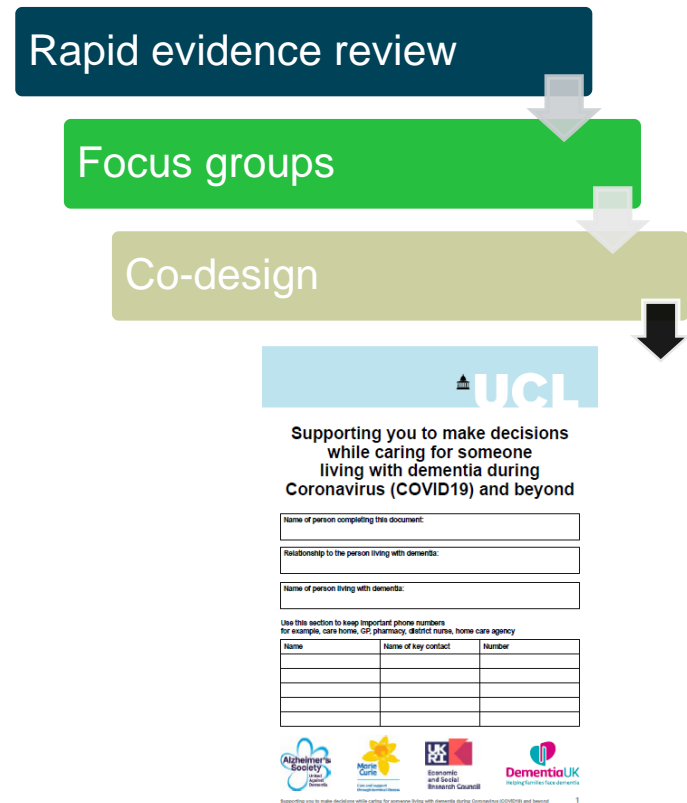
	With all patients	With all carers	Leaflet	On request
The nature of dementia as a progressive illness	87%	89%	87%	35%
The nature of dementia as a terminal illness	37%	41%	48%	63%
Spirituality or interpretations of the meaning of death	11%	11%	17%	63%
The meaning and implications of loss of mental capacity	59%	61%	67%	57%
Discussions about the patient's wishes for the future	67%	63%	67%	54%

# Supporting decision making

- Decision aids

- Videos, booklets, or web-based tools
- State the decision, provide information, summarize options, benefits and harms
- Helps guide decision by clarifying values
- Increase knowledge, quality of communication, effective in reducing decisional conflict

Davies et al. 2019





# Working with the current reality

Refer to palliative care

Creative partnerships

Use the frailty agenda-  
Rockwood frailty index

Assessment IS intervention

Introduce the idea that dementia is a “life limiting illness”

Use a philosophy of “living well” AND “dying well”

Discussion is the likely active ingredient of ACP

# Resources

Fox et al. *BMC Palliative Care* (2018) 17:9  
 DOI 10.1186/s12904-017-0221-0

BMC Palliative Care

DEBATE

Open Access



## Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research

Siobhán Fox<sup>1\*</sup>, Carol FitzGerald<sup>1</sup>, Karen Harrison Dening<sup>2</sup>, Kate Irving<sup>3</sup>, W. George Kernohan<sup>4</sup>, Adrian Treloar<sup>5</sup>, David Oliver<sup>6,7</sup>, Suzanne Guerin<sup>8</sup> and Suzanne Timmons<sup>1</sup>

## Components of a community model of dementia palliative care

Siobhan Fox and Niamh O'Connor

*Centre for Gerontology and Rehabilitation, University College Cork, Cork, Ireland*

Johnathan Drennan

*School of Nursing and Midwifery, University College Cork, Cork, Ireland*

Suzanne Guerin

*School of Psychology, University College Dublin, Dublin, Ireland*

W. George Kernohan

*Institute of Nursing and Health Research, Ulster University, Belfast, UK*

Aileen Murphy

*School of Economics, University College Cork, Cork, Ireland, and*

Suzanne Timmons

*Centre for Gerontology and Rehabilitation, University College Cork, Cork, Ireland*

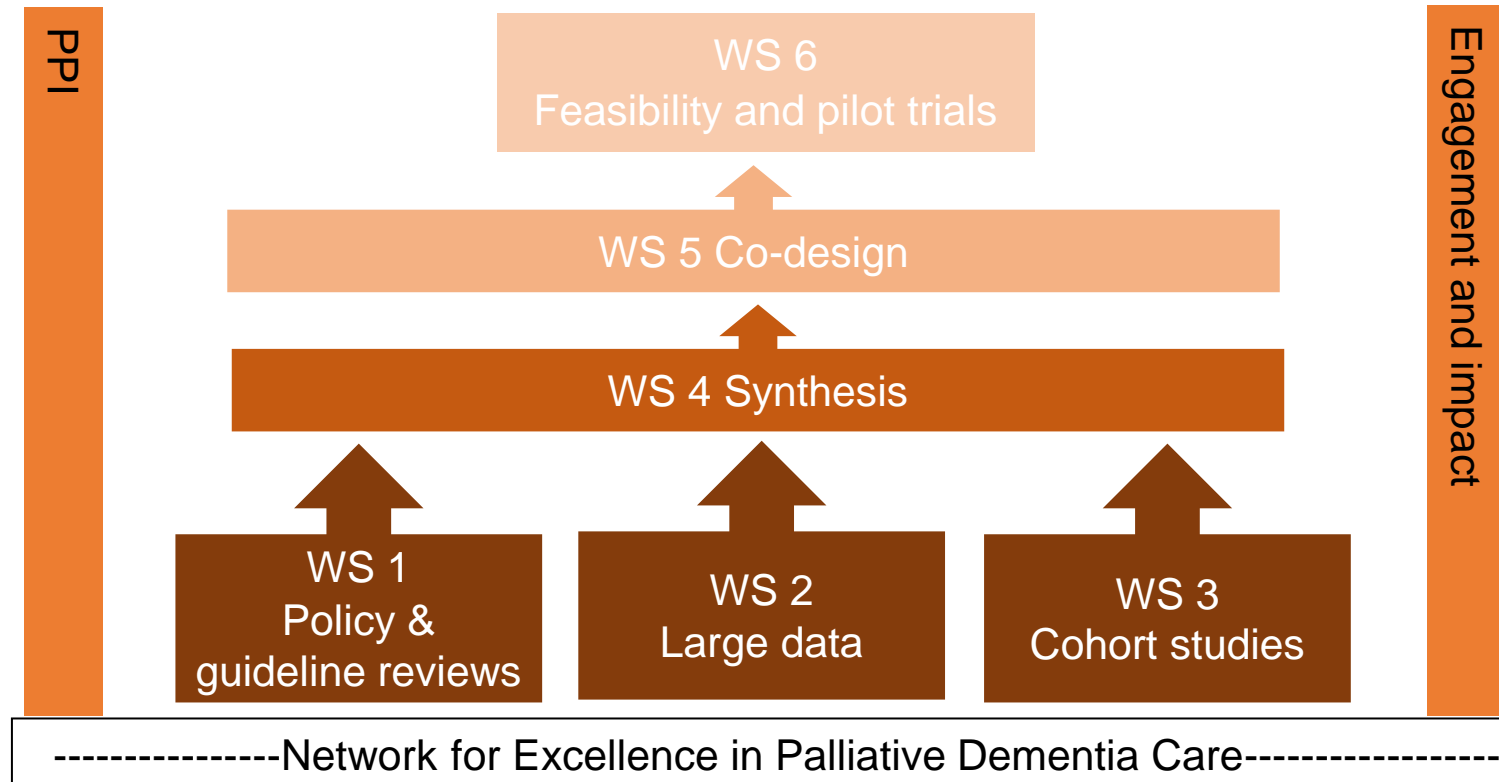
Community  
 model of  
 dementia  
 palliative care

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Received 14 February 2020  
 Revised 6 May 2020  
 19 May 2020  
 Accepted 28 May 2020



# Empowering Better End of life Dementia Care (EMBED-Care)



**Thank you**



**@proflizsampson**

<https://www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research-department/research/centre-dementia-palliative-care>