



Dementia care & Palliative care: during and beyond the COVID-19 pandemic

Monday 12 October 2020

08:00 EDT New York | 13:00 BST London | 22:30 ACST Adelaide

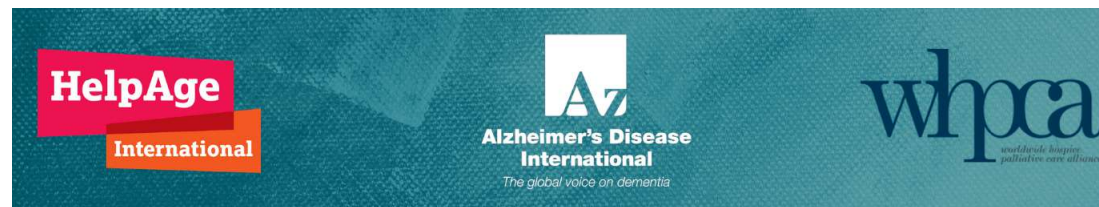
Welcome and introductions



Paola Barbarino
Chief Executive, ADI

Agenda

- **Christine Thelker** – Dementia advocate and member of Dementia Alliance International from Canada
- **Dr Stephen Connor** – Executive Director, Worldwide Hospice Palliative Care Alliance (WHPCA)
- **Justin Derbyshire** – Chief Executive, HelpAge International
- **Dr Zipporah Ali** - Executive Director, Kenya Hospices Palliative Care Association; Board Member of WHPCA and Alzheimer's & Dementia Organisation Kenya (ADOK)




Agenda

- **Pao Pheng** – Caregiver from Indonesia
- **Dr Liz Sampson** – Principal Investigator, EMBED (Empowering Better End of Life Dementia Care), University College London
- **Dr Adam Gordon** – Vice President of Academic Affairs, British Geriatrics Society and Professor of the Care of Older People, University of Nottingham
- **Poll**
- **Question & answer session**

Poll





Christine Thelker

Board member of Dementia
Alliance International (DAI)

Dementia advocate from Canada



@AlzDisInt

@HelpAge

@whpca

Dementia, Palliative Care and COVID-19

Christine Thelker

Board member, Dementia Alliance International

Author, Advocate, Speaker

- info@infodai.org
- www.infodai.org
- @ChrissyThelker
- @DementiaAllianc



Key points

- Palliative Care
- Advanced Care Directive
- The impact of the Coronavirus pandemic

Support and Advocacy, of, by and for people with dementia

01

Join a DAI online peer-to-peer support group today.
www.joindai.org

02

Facetime, Zoom, or Skype with family and friends.

03

Follow ADI's up to date advice and resource page.
www.alz.co.uk

04

Follow the World Health Organisation daily updates.
www.who.int



**DEMENTIA
ALLIANCE
INTERNATIONAL**

**FOR PEOPLE
WITH DEMENTIA
DURING THE
COVID-19
PANDEMIC**

DAI has a 24/7 open access Zoom room available for members, family and friends.

www.infodai.org | email: info@infodai.org

Join your peers, family and friends at DAI's monthly Café Lé Brain & Webinars.

05

Contact your national Alzheimer's organisation.

06

Exercise daily.

07

Maintain physical distancing and stay safe.

08

The lack of care and of change

I am more frightened by the thought of ending up in any type of care than I ever have been of my dementia itself.

*As an advocate, I don't just want to feel good about what what I am doing, I want **tangible change**.*

(Christine Thelker, 2020)

Support and Advocacy, of, by and for people with dementia



Thank you



Support and Advocacy, of, by and for people with dementia



DEMENTIA ALLIANCE INTERNATIONAL

- Free membership for people with dementia
- Online peer to peer support groups
- Living Alone social support groups
- Monthly online Cafés and meetings
- Monthly Educational Webinars
- Reports and Publications
- Award-winning YouTube Channel
- Active social media



Support and Advocacy, of, by and for people with dementia

Dr Stephen Connor

Executive Director, Worldwide
Hospice Palliative Care Alliance
(WHPCA)



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Dementia care & Palliative care: during and beyond the COVID-19 pandemic

Dr. Stephen R Connor
Executive Director – WHPCA

Alzheimer's Disease International
HelpAge
WHPCA
12 October 2020



Global Atlas of Palliative Care

2nd Edition



The need - a global perspective

- >1 million deaths/week
- Almost 57 million need
 - 25.7M at EOL
- 76% LMIC
- 67% 50+ / 7% children
- only 15% of countries good integration
- Families (at least 2-4 each)



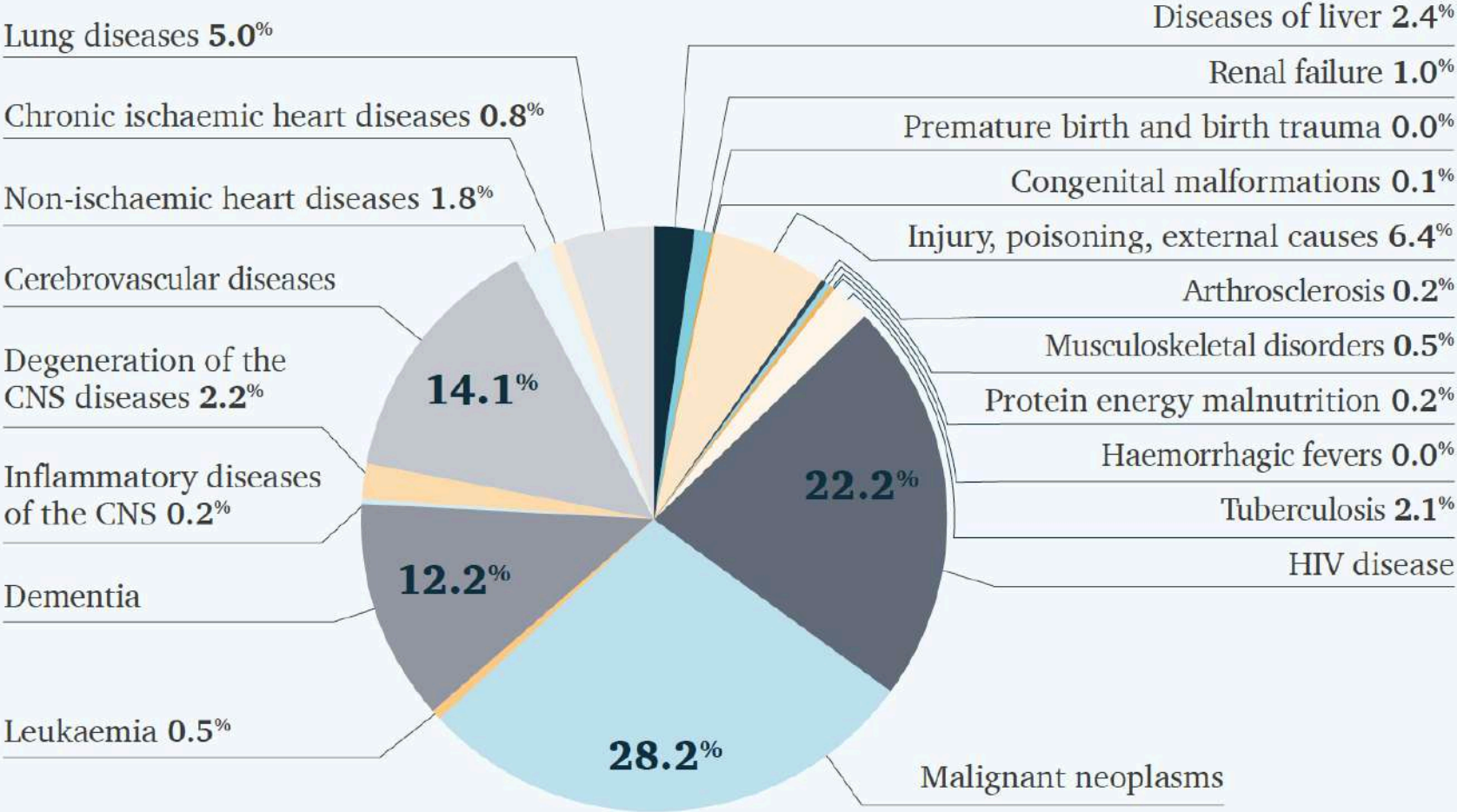
Global Palliative Care Delivery

- 7 million receiving PC
12% of need for PC met
- 25,000 PC services
- 64% of countries no or limited PC delivery
- 83% of countries have low to non-existent access to opioids for pain relief



Figure 5
**Worldwide need for
palliative care for
adults by disease
groups (20+ years
2017)**

N = 52,883,093 adults



Dementia and Palliative Care

- Approx. 6.5 million (4M in LMICs & 2.5M in HICs) 12.2% need
 - 2M @end of life – 4.5M prior to EOL
- The condition with the highest proportional increase in serious-related suffering will be dementia (264% increase between 2016 and 2060).
- COVID-19 adds several complications for PLWD including:
 - Increased need for caregiver support and respite
 - Safety and protection from infection
 - Aggressive management of symptoms



Dementia and Palliative Care

- Equitable Access to Palliative Care
 - PLWD, including older must have equal access
- Human Rights
 - Freedom of choice, access to trained professionals
- Political Will
 - All advocates & practitioners need to work together UHC
- Indicators
 - Improved national & global monitoring



Justin Derbyshire

Chief Executive, HelpAge
International



@AlzDisInt

@HelpAge

@whpca

**The impact of
COVID-19 on
older people:
access to
health and
care services
and support**

HelpAge

International



Older people's risk from COVID-19

94%

of all deaths

were in persons aged 60+

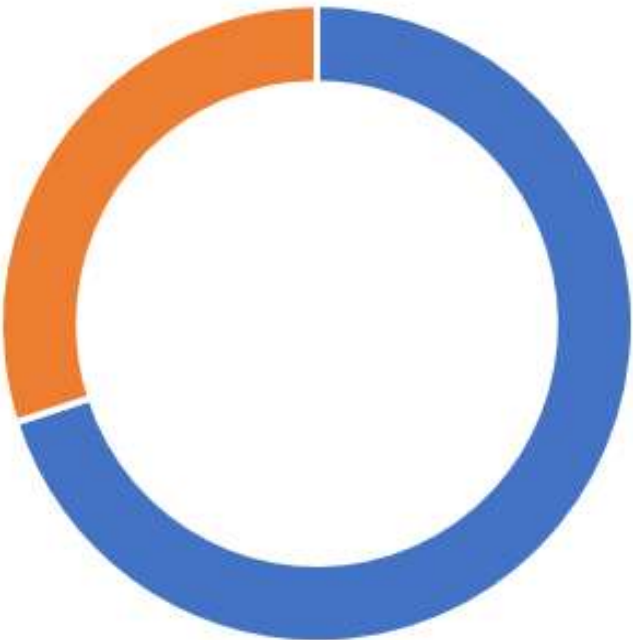
79%

of all ICU admissions were
people aged 50-79 years

Country	Age range	% of total deaths
Bangladesh	50 and over	69
Canada	60 and over	97
Eswatini	50 and over	73
Moldova	60 and over	77
Myanmar	60 and over	67
USA	50 and over	95
Vietnam	60 and over	63

Age, gender and co-morbidities

Underlying health condition

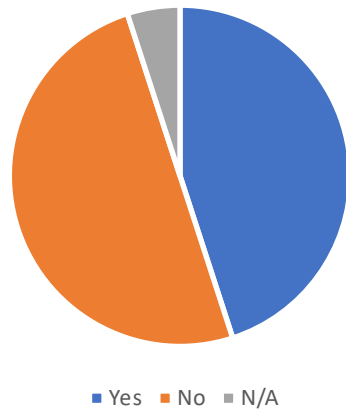


■ Yes ■ No

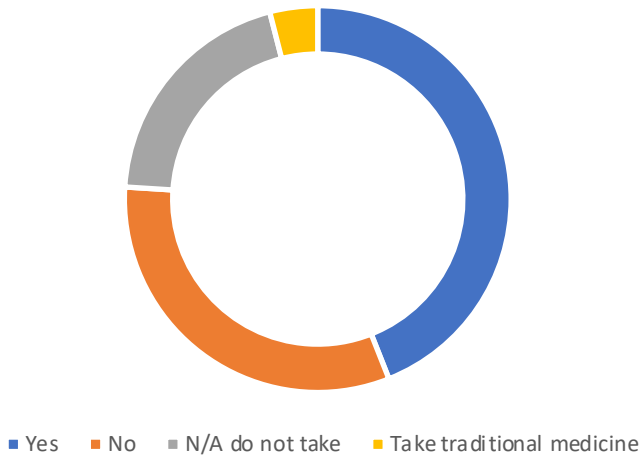
Country	Age	Deaths per 100,000	
		M	F
Bangladesh	80+	48	12
Canada	80+	409	399
Haiti	80+	49	16
Kyrgyzstan	80+	31	9
Moldova	80+	283	139
Pakistan	80+	32	10
Philippines	80+	93	48

Access to health services during COVID-19

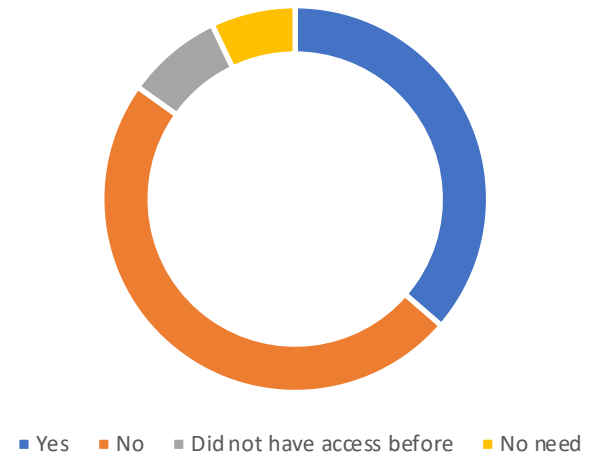
Know where the nearest health facility is for COVID-19 testing and treatment



Able to access medication



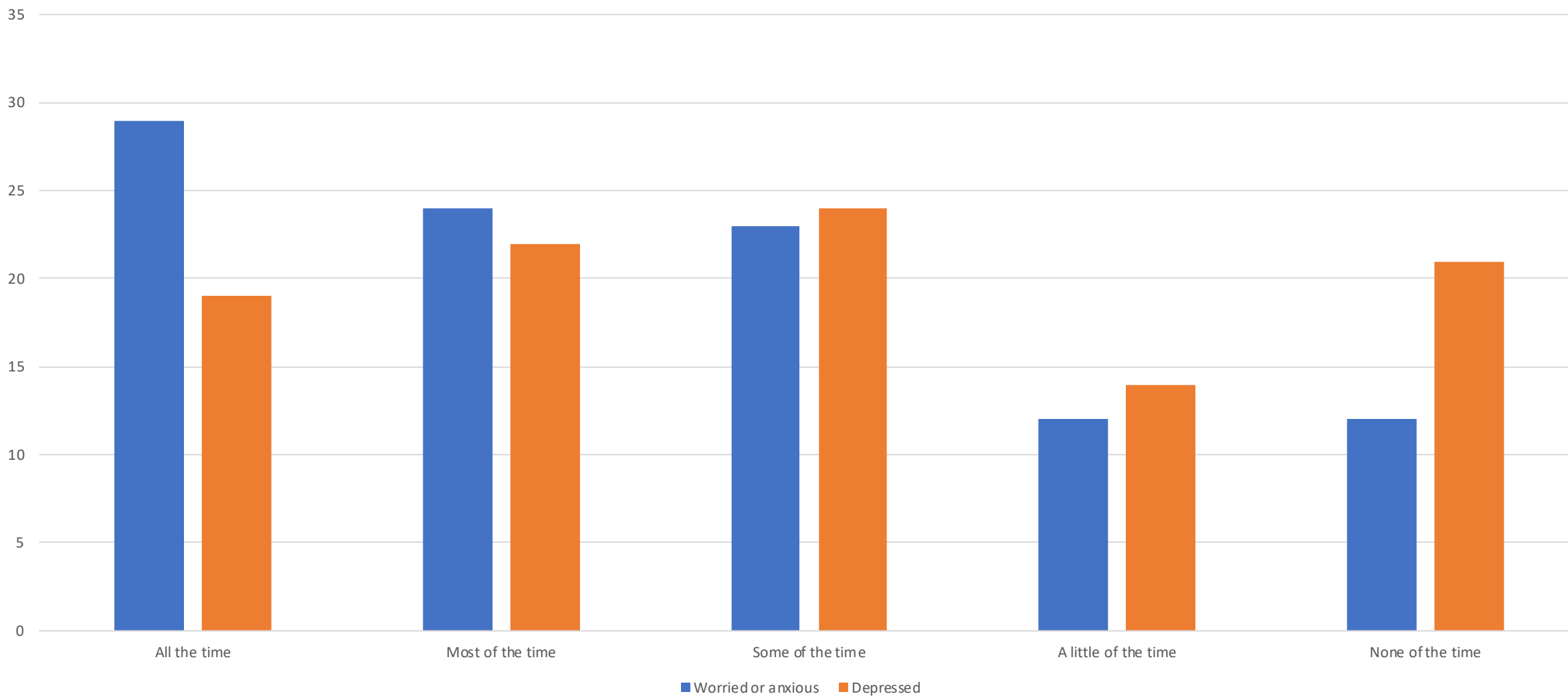
Change in access to health services



Impact on older people's health and wellbeing

HelpAge

International



HelpAge response



COVID-19: end of life care at home

Guidance for family members and friends



www.helpage.org/what-we-do/coronavirus-covid19/



COVID-19: Guidance and advice for carers of older people at home



Psychosocial support for older people in the context of COVID-19



Dr Zipporah Ali

Executive Director, Kenya
Hospices Palliative Care
Association

Board Member of WHPCA and
Alzheimer's & Dementia
Organisation Kenya (ADOK)



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@HelpAge

@whpca

Dementia and palliative care in low- & middle- income countries

Zipporah Ali. MD. MPH. MPC. HonDUniv

Executive Director

Kenya Hospices and Palliative Care Association

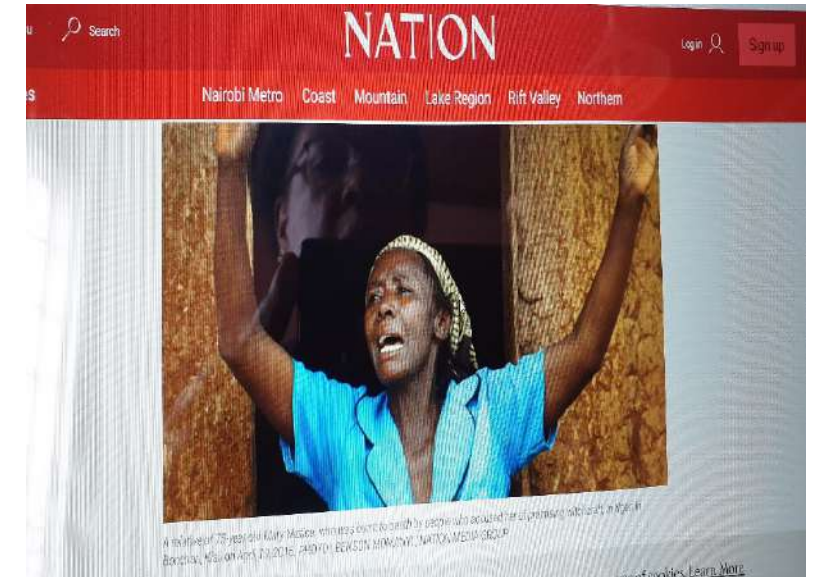
zippy@kehpca.org

Why do older people get less palliative care than younger people? Anna Lloyd et al 2016)

- WHO claims that older people suffer because of **a lack of access to palliative**
- Older people can be considered to have less palliative care needs by virtue of **death being more expected.**
- They may be unwilling to accept care that they perceive **might threaten their independence.**
- Older people with cancer may receive less adequate pain relief
- Older people may receive **less emotional and spiritual support** and be **subjected to more unwanted treatment decisions.**
- Hunt et al also found that those over 85 years of age were less likely to have their **preferences for place of death recorded**, or to actually die there

What are some of the challenges to accessing palliative care for persons with dementia?

- Palliative care across all ages is not yet fully integrated in our health care systems, still considered a new concept
- Dementia Care is generally not well integrated in our health care systems and has not been a priority.
 - Lack of information to the public (**lynched, burnt, stoned etc**)
 - Lack of education for HCPs (diagnosis, treatment including **palliative & supportive care**, follow up)
 - Lack of policies, strategies that focus on older persons
 - No allocated budget to support older persons with dementia
 - Not enough support groups for patients/ families



Ongoing Project in Kenya

- Strengthening responses to dementia in Developing Countries (STRiDE)
- Africa Mental Health Research and Training Foundation (AMHR)
- Global
- Alzheimer's/Dementia Organization Kenya (ADOK)
- Challenges Research Found (GCRF)
- Ministry of Health –Kenya (MoH)
- University of Nairobi (UoN)
- Global Challenges Research Fund (GCRF)

Intention to come up with a country Dementia Plan that will address all aspects (Awareness, education, prevention, treatment including palliative care)



Conclusion

- There is a need for changing the mind-set of people and creating awareness in the health care sector, so that more older persons including those with dementia can access palliative care services, as there is no specific program integrated for older persons.
- Have policies and plans specific for older persons and dementia
- Ensure that Dementia is part of our UHC and our National Health Insurance Fund
- **Advocate for Hospice and Palliative Care to fully integrate PC care for the older persons (and their families) with dementia**



Pao Pheng

Caregiver from Jakarta, Indonesia



@AlzDisInt

@HelpAge

@whpca

Into the Purple Sky

My Caregiving Journey



Pao Pheng
Caregiver for Her Dementia Mother
Jakarta, Indonesia

Being a caregiver to both parents on their palliative stage of Dementia

- Embrace them
- Seek help and connect
- Love yourself, too





The journey of
caring brings me
to the top the
world

Sharing my journey
to spread
awareness and
strengthen others



19 September 14.00-15.30

Let's Talk About Dementia

Menciptakan Kehidupan yang Bermakna

Bagi Orang Dengan Demensia dan Family Caregivers

Bintang Tamu:
Widyawati - Pekerja Seni
Gina S. Noer - Penulis Naskah & Sutradara Film

Fasilitator:
Amalia Fonk-Utomo
Gery Puraatmadja

Media: ZOOM Meeting | Registrasi: bit.ly/WAM19SEP20



Malam ini jam 7-9

Ngomandan!

Jangan Maklum dengan Pikun "Pahami DEMENSIA"

Narasumber:
Michael Dirk Roelf Maltimo, M.Si, Psikolog
(Direktur Eksekutif Alzheimer Indonesia)

Moderator:
Danny Hermawan

30 RABU
September
2020
19.00 - 21.00 WIB

Join Via zoom : 896 3413 2687
Passcode : NGOMANDAN



World Alzheimer's Month
Let's Talk About Dementia
19 September 2020

Alzheimer's Indonesia



bakti BCA

Mentori Kesehatan RI, Dr. Terawan Agus Putranto
Widyawati (Pekerja Seni) Andri F. Noer (BenihBak.com)
Gina S. Noer (Sutradara Film), Pao Mandikin (Caregiver)
DY Suharya (ALZ/ADI)
Paula Barbarino (CEO Alzheimer's Disease Int.)
Glenn Rees (Chairman Alzheimer's Disease Int.)
Gery Puraatmadja & Amalia Fonk-Utomo (Host)

Phodis L'OREAL INDONESIA
Maverick ATMA JAYA FEMALE

Thank you!

#DoNotUnderestimateMemoryLoss

#JanganMaklumDenganPikun



Everest for ALZI 2019



@everestforalzi2019

Dr Liz Sampson

Principal Investigator, EMBED
(Empowering Better End of Life
Dementia Care), University
College London



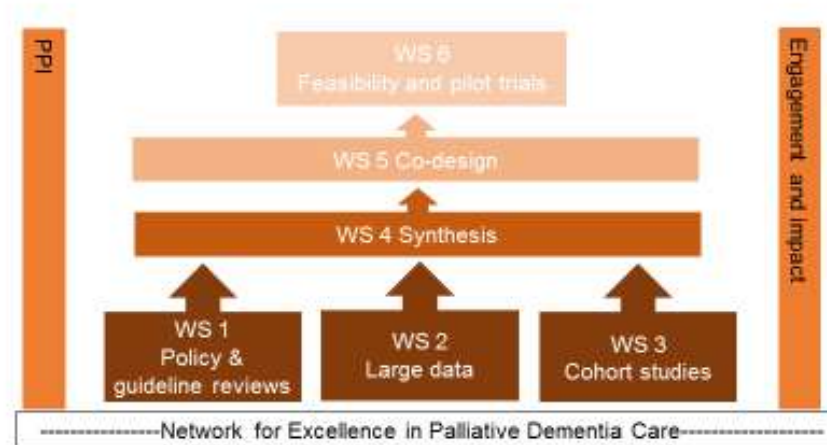
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Improving end of life care for people with dementia

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



Professor Liz Sampson MCPCRD, UCL, London
Liaison Psychiatry, North Middlesex University Hospital
e.sampson@ucl.ac.uk @drlizsampson

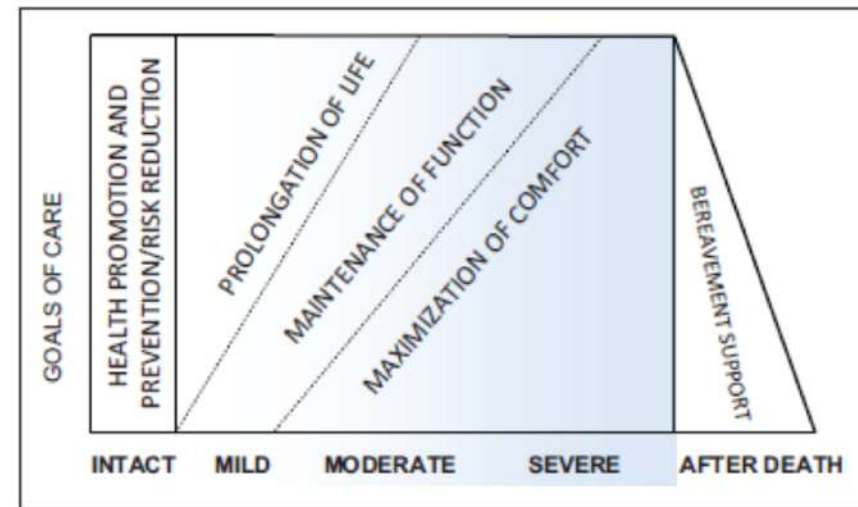
What is palliative care ?

*“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



EAPC White Paper on
Dementia and Palliative care

Palliative care, dementia and COVID

Symptoms at Referral	N =
Breathlessness	101
Agitation	67
Drowsiness	43
Pain	36
Delirium	23
Secretions	24
Fatigue	11
Fever	9
Cough	9
Other symptoms	4
	12

Lovell et al 2020

Maximise comfort & quality of life

Needs-based approach

Assessment and management of physical symptoms

Managing distress & containing uncertainty

Impact on families, friends and staff



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

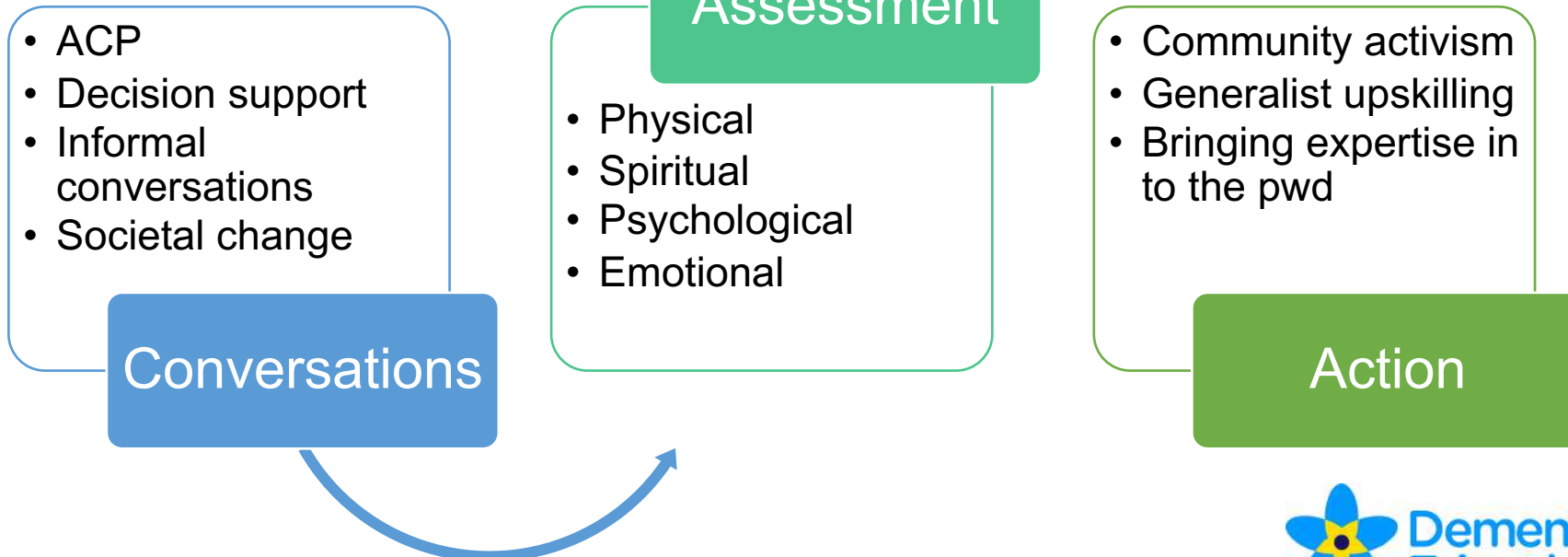
Dame Cicely Saunders

- Anticipatory, pre-bereavement and complicated grief
- Prolonged period without visiting
- “Aggressive” care for the person with dementia associated with worse bereavement experiences
- Unable to grieve within usual culture, religion and norms
- Moral distress in staff

Getting it right



<https://pos-pal.org/>



Dr Adam Gordon

Vice President of Academic
Affairs, British Geriatrics Society

Professor of the Care of Older
People, University of Nottingham



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**University of
Nottingham**

UK | CHINA | MALAYSIA

Dementia Care During and After COVID-19

The perspective from Clinical Gerontology

**Adam Gordon,
Professor of the Care of Older People
University of Nottingham, UK**



@adamgordon1978

Covid ban on care home visitors risks premature deaths, experts warn

Charities call for elderly residents' loved ones to be given limited visiting rights to maintain 'will to live'

● [Coronavirus - latest updates](#)

● [See all our coronavirus coverage](#)



▲ Family visitors can be crucial in helping people with dementia to eat properly, says the Alzheimer's Society.
Photograph: David Pereiras/Getty Images/EyeEm

Sweeping bans on visiting at thousands of care homes risk residents dying prematurely this winter as they give up hope in the absence of loved ones, experts in elderly care have warned.

Belfast Telegraph

Coronavirus: Lock down care homes, urges Jim Wells



Jim Wells



Andrew Madden  

October 10 2020 07:00 AM



Former Health Minister Jim Wells has said he supports a Covid strategy that would see a "ring of steel" placed around Northern Ireland care homes, allowing young people to avoid a second lockdown.

That is despite the fact it would mean the South Down MLA would not be able to visit his vulnerable wife.



Ads by Google

Stop seeing this ad

Why this ad?

Care homes are waiting up to **THREE WEEKS** to get their coronavirus test results as bosses warn the swabbing system is 'getting worse'

- Government had promised to get care home employees swabbed every week
- And also get residents tested for the virus every 28 days to detect transmission
- But the testing system is failing to turn around the tests quickly enough
- At some homes staff are being swabbed before receiving results from last test

Coronavirus testing scheme could allow care home visitors to hug relatives

In-home saliva testing machines offering quick results may be 'game-changer' for guidelines and allow physical contact

By Gabriella Swerling, SOCIAL AND RELIGIOUS AFFAIRS EDITOR

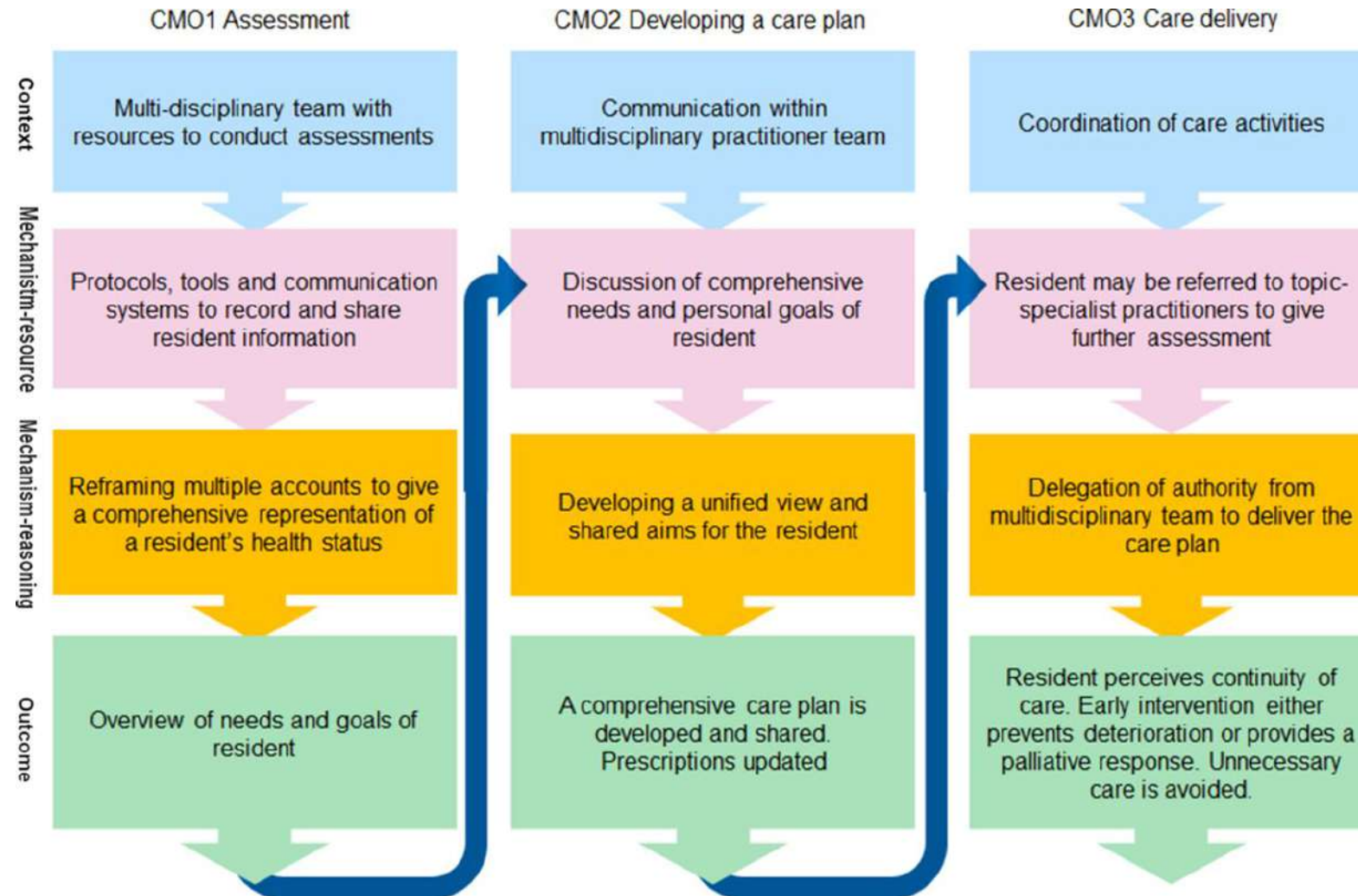
23 September 2020 • 5:15pm

Reaction Overview				Operator:ROSELIN ANTReport No:2020092410!		
	Sample ID	Extraction Lot No.	Reagent Lot No.	Target	Target Result	IC Result
A	AAC04984712	0702209	SCoV2orf1a...	SCoV...	-	+
B	TAAC04984...	0702209	SCoV2orf1a...	SCoV...	-	+
C	AAB82167244	0702209	SCoV2orf1a...	SCoV...	-	+
D	AAB82167039	0702209	SCoV2orf1a...	SCoV...	-	+
E	AAB82167343	0702209	SCoV2orf1a...	SCoV...	-	+
F	AAC04984958	0702209	SCoV2orf1a...	SCoV...	-	+
G	AAC04984699	0702209	SCoV2orf1a...	SCoV...	-	+
H	POS CON	0702209	SCoV2orf1a...	SCoV...	+	+
UV Treatment Is Completed				Save to USB	End	

Extended care in care homes

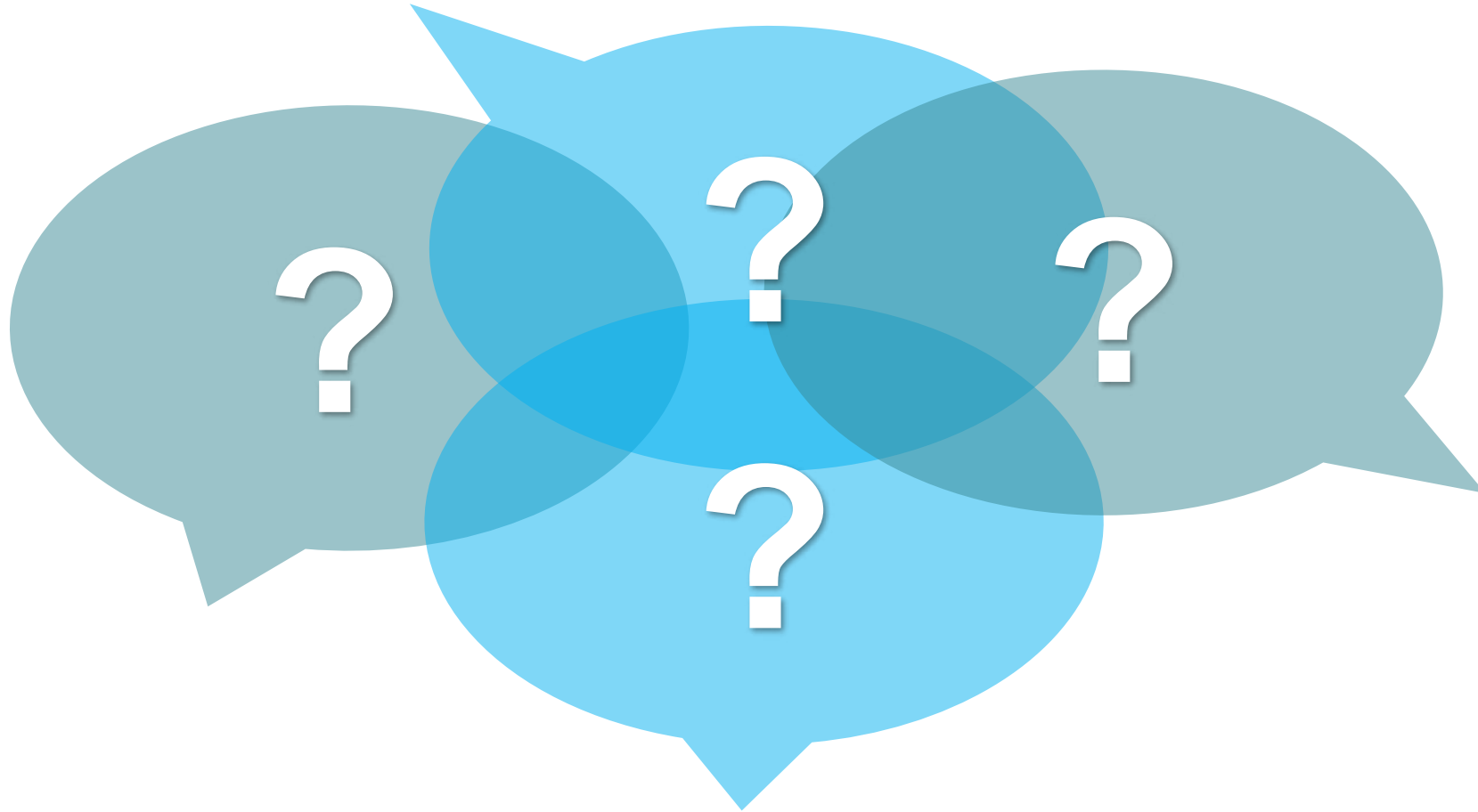
- A choice between hospital and palliation is a false dichotomy if you can deliver active care in care homes.
- Oxygen can be provided up to 9L/min with appropriate safety measures in place.
- If you can provide oxygen, you can open up access to dexamethasone.
- Subcutaneous fluids may have a role if staff can develop necessary competencies.
- Enoxaparin remains an area of uncertainty.

How Comprehensive Geriatric Assessment Works in a Care Home



Neil H Chadborn et al. *BMJ Open* 2019;9:e026921

Question and answer



Poll

**What word best describes
your feelings regarding
palliative care & dementia care**

61 26 40 6

<https://www.menti.com/rti8gqms34>



Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

10-12 December 2020
VIRTUAL CONFERENCE



**VIRTUAL
2020**

ALZHEIMER'S DISEASE INTERNATIONAL
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HelpAge

International



**Alzheimer's Disease
International**

The global voice on dementia

whpca
worldwide hospice
palliative care alliance



Thank you for joining us

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