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)
• 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

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

https://www.menti.com
Christine Thelker

Board member of Dementia Alliance International (DAI)

Dementia advocate from Canada
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
Join a DAI online peer-to-peer support group today. www.joindai.org

Facetime, Zoom, or Skype with family and friends.

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

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

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

Contact your national Alzheimer’s organisation.

Exercise daily.

Maintain physical distancing and stay safe.

DAI has a 24/7 open access Zoom room available for members, family and friends. www.infodai.org | email: info@infodai.org

DAI Vision: A world where all people are valued and included
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 I am doing, I want tangible change.

(Christine Thelker, 2020)
Thank you

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)

@AlzDisInt  @HelpAge  @whpca
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
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)

- Lung diseases 5.0%
- Chronic ischaemic heart diseases 0.8%
- Non-ischaemic heart diseases 1.8%
- Cerebrovascular diseases
- Degeneration of the CNS diseases 2.2%
- Inflammatory diseases of the CNS 0.2%
- Dementia
- Leukaemia 0.5%
- Malignant neoplasms 28.2%
- Diseases of liver 2.4%
- Renal failure 1.0%
- Premature birth and birth trauma 0.0%
- Congenital malformations 0.1%
- Injury, poisoning, external causes 6.4%
- Arteriosclerosis 0.2%
- Musculoskeletal disorders 0.5%
- Protein energy malnutrition 0.2%
- Haemorrhagic fevers 0.0%
- Tuberculosis 2.1%
- HIV disease

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
  • Safely 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
The impact of COVID-19 on older people: access to health and care services and support
Older people’s risk from COVID-19

<table>
<thead>
<tr>
<th>Country</th>
<th>Age range</th>
<th>% of total deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bangladesh</td>
<td>50 and over</td>
<td>69</td>
</tr>
<tr>
<td>Canada</td>
<td>60 and over</td>
<td>97</td>
</tr>
<tr>
<td>Eswatini</td>
<td>50 and over</td>
<td>73</td>
</tr>
<tr>
<td>Moldova</td>
<td>60 and over</td>
<td>77</td>
</tr>
<tr>
<td>Myanmar</td>
<td>60 and over</td>
<td>67</td>
</tr>
<tr>
<td>USA</td>
<td>50 and over</td>
<td>95</td>
</tr>
<tr>
<td>Vietnam</td>
<td>60 and over</td>
<td>63</td>
</tr>
</tbody>
</table>

94% of all deaths were in persons aged 60+

79% of all ICU admissions were people aged 50-79 years
### Age, gender and co-morbidities

<table>
<thead>
<tr>
<th>Country</th>
<th>Age</th>
<th>Deaths per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>80+</td>
<td>48</td>
</tr>
<tr>
<td>Canada</td>
<td>80+</td>
<td>409</td>
</tr>
<tr>
<td>Haiti</td>
<td>80+</td>
<td>49</td>
</tr>
<tr>
<td>Kyrgyzstan</td>
<td>80+</td>
<td>31</td>
</tr>
<tr>
<td>Moldova</td>
<td>80+</td>
<td>283</td>
</tr>
<tr>
<td>Pakistan</td>
<td>80+</td>
<td>32</td>
</tr>
<tr>
<td>Philippines</td>
<td>80+</td>
<td>93</td>
</tr>
</tbody>
</table>
Access to health services during COVID-19

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

- Yes
- No
- N/A

Able to access medication

- Yes
- No
- N/A do not take
- Take traditional medicine

Change in access to health services

- Yes
- No
- Did not have access before
- No need
Impact on older people’s health and wellbeing

- Worried or anxious
- Depressed
HelpAge response

COVID-19: end of life care at home
Guidance for family members and friends

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

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

www.helpage.org/what-we-do/coronavirus-covid19/
Dr Zipporah Ali

Executive Director, Kenya Hospices Palliative Care Association

Board Member of WHPCA and Alzheimer's & Dementia Organisation Kenya (ADOK)
Dementia and palliative care in low- & middle-income countries

Zipporah Ali. MD. MPH. MPC. HonDUniv
Executive Director
Kenya Hospices and Palliative Care Association
zippy@keh pca.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
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

@AlzDisInt  @HelpAge  @whpca
Improving end of life care for people with dementia

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

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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
Maximise comfort & quality of life

Needs-based approach

Assessment and management of physical symptoms

Managing distress & containing uncertainty

Symptoms at Referral

<table>
<thead>
<tr>
<th>Symptom</th>
<th>N = 101</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathlessness</td>
<td>67</td>
</tr>
<tr>
<td>Agitation</td>
<td>43</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>36</td>
</tr>
<tr>
<td>Pain</td>
<td>23</td>
</tr>
<tr>
<td>Delirium</td>
<td>24</td>
</tr>
<tr>
<td>Secretions</td>
<td>11</td>
</tr>
<tr>
<td>Fatigue</td>
<td>9</td>
</tr>
<tr>
<td>Fever</td>
<td>9</td>
</tr>
<tr>
<td>Cough</td>
<td>4</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>12</td>
</tr>
</tbody>
</table>

Lovell et al 2020
Impact on families, friends and staff

• 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

“How people die remains in the memory of those who live on”
Dame Cicely Saunders
Getting it right

- ACP
- Decision support
- Informal conversations
- Societal change

Assessment
- Physical
- Spiritual
- Psychological
- Emotional

Action
- Community activism
- Generalist upskilling
- Bringing expertise in to the pwd

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

@AlzDisInt  @HelpAge  @whpca
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.
Coronavirus: Lock down care homes, urges Jim Wells

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.
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
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

CMO1 Assessment

Context: Multi-disciplinary team with resources to conduct assessments

Mechanism-resource: Protocols, tools, and communication systems to record and share resident information

Mechanism-reasoning: Reframing multiple accounts to give a comprehensive representation of a resident's health status

Outcome: Overview of needs and goals of resident

CMO2 Developing a care plan

Context: Communication within multidisciplinary practitioner team

Mechanism-resource: Discussion of comprehensive needs and personal goals of resident

Mechanism-reasoning: Developing a unified view and shared aims for the resident

Outcome: A comprehensive care plan is developed and shared. Prescriptions updated

CMO3 Care delivery

Context: Coordination of care activities

Mechanism-resource: Resident may be referred to topic-specialist practitioners to give further assessment

Mechanism-reasoning: Delegation of authority from multidisciplinary team to deliver the care plan

Outcome: Resident perceives continuity of care. Early intervention either prevents deterioration or provides a palliative response. Unnecessary care is avoided.


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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.

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10-12 December 2020
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Thank you for joining us

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