



**Alzheimer's Disease  
International**

*The global voice on dementia*

**ADI webinar on**  
***The hidden casualties of COVID-19: revealing the emergency  
in care homes and the lessons learnt in day care***

**Wednesday 3 June**

# Welcome and introductions



**Paola Barbarino**

CEO,

Alzheimer's Disease International (ADI)



# Poll

*Who is taking part in this  
webinar?*



# ADI Emergency Appeal



**During this COVID-19 emergency period  
please make a donation, however large or small,  
to ensure we can continue to make a real difference.**

**ADI will continue to help people living with dementia  
and their carers to live a better life during this emergency.**

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# Welcome and introductions



**Paola Barbarino**

CEO,

Alzheimer's Disease International (ADI)

# Speakers

- Dale Goldhawk, Alzheimer's Disease International
- Adelina Comas-Herrera, London School of Economics and Political Science (LSE)
- Lyn Rogers, person living with dementia, Australia
- Philip Connaughton, carer, Ireland
- Martin Jones, Home Instead Senior Care UK
- Saskia Sivananthan, Alzheimer Society of Canada
- Wendy Weidner, Alzheimer's Disease International (ADI)
- Alison Dawson, Faculty of Social Sciences, University of Stirling
- Meera Pattabiraman, Alzheimer's & Related Disorders Society of India (ARDSI)

# Dale Goldhawk

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Vice-Chair & Chair-Elect,  
Alzheimer's Disease International



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# Adelina Comas-Herrera

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Assistant Professorial Research  
Fellow, Care Policy and  
Evaluation Centre, London School  
of Economics and Political  
Science (LSE)



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# COVID-19 and people who live in care homes: what has happened and what can done?

Adelina Comas-Herrera

3<sup>rd</sup> June 2020

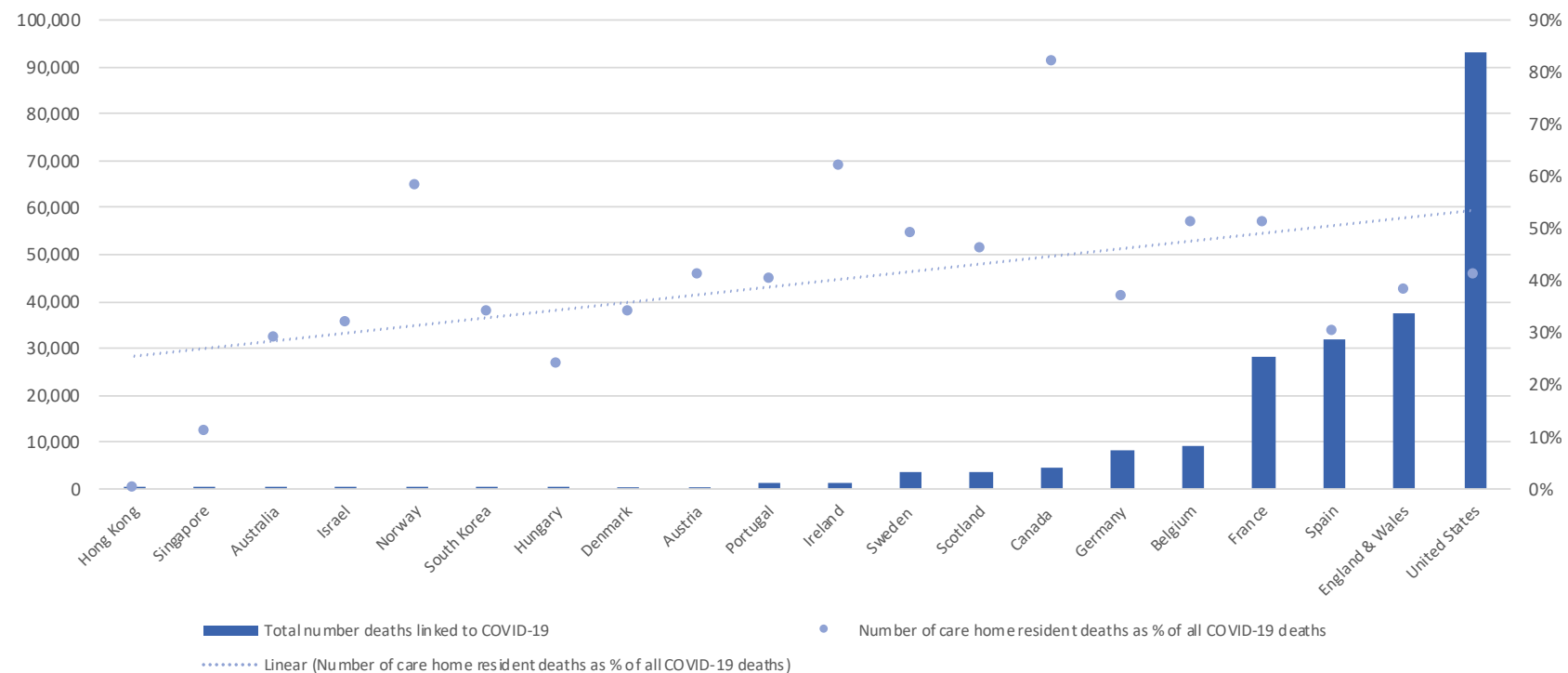
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[a.comas@lse.ac.uk](mailto:a.comas@lse.ac.uk), @adelinacohe

# Why do we need to know about deaths of care home residents linked to COVID-19?

- In many countries, care homes not included in initial responses to COVID-19.
- Focus was on stopping transmission in the community and boosting hospital capacity, but situation was different in countries in Asia with SARS and MERS experience: strong Infection Prevention and Control systems in care homes.
- No data on number of people infected (and deceased) in care homes:  
**risk that vital resources needed to tackle infections in care homes are not made available**

Data from 19 countries: the higher the total number of deaths, the larger the share of people who die in care homes



Comas-Herrera A, Zalakaín J, Litwin C, Hsu AT, Lane N and Fernández J-L (2020) *Mortality associated with COVID-19 outbreaks in care homes: early international evidence*. LTCcovid, International Long-Term Care Policy Network, CPEC-LSE, 21 May 2020. <https://ltccovid.org/wp-content/uploads/2020/05/Mortality-associated-with-COVID-21-May-7.pdf>

# What have we learnt?

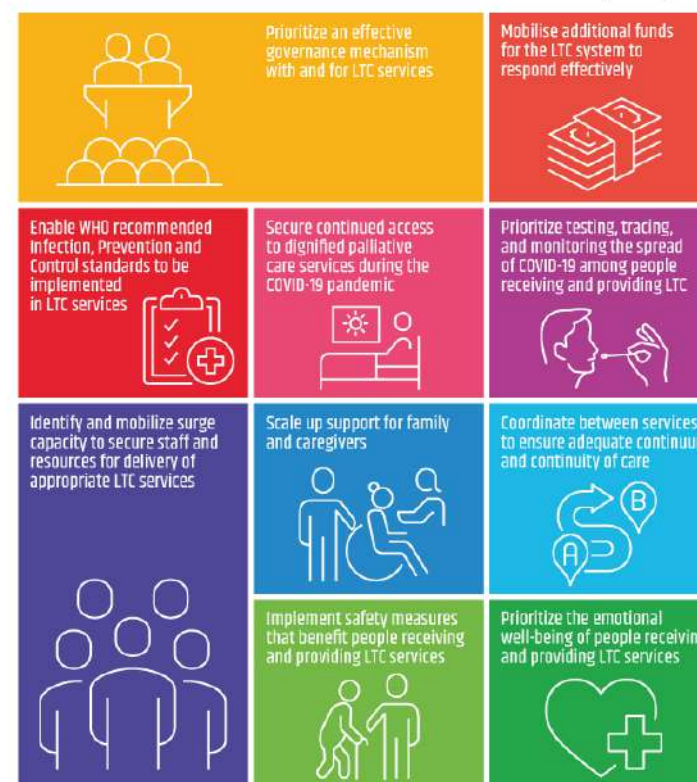
- Very important to measure and report number of deaths of care home residents during the COVID-19 pandemic
- Share of total deaths in homes are important to:
  - Show potential underestimation of total deaths (specially if only confirmed cases or deaths in hospitals are counted)
  - Improve allocation of (potentially scarce) resources: testing, PPE, nurses, quarantine facilities, technical support, etc.
- Shares of total care home residents offer a different perspective on the impact of COVID-19 on care home residents
- We also need to understand other impacts:
  - Staff, people who rely on care in the community
  - Physical and mental health impacts



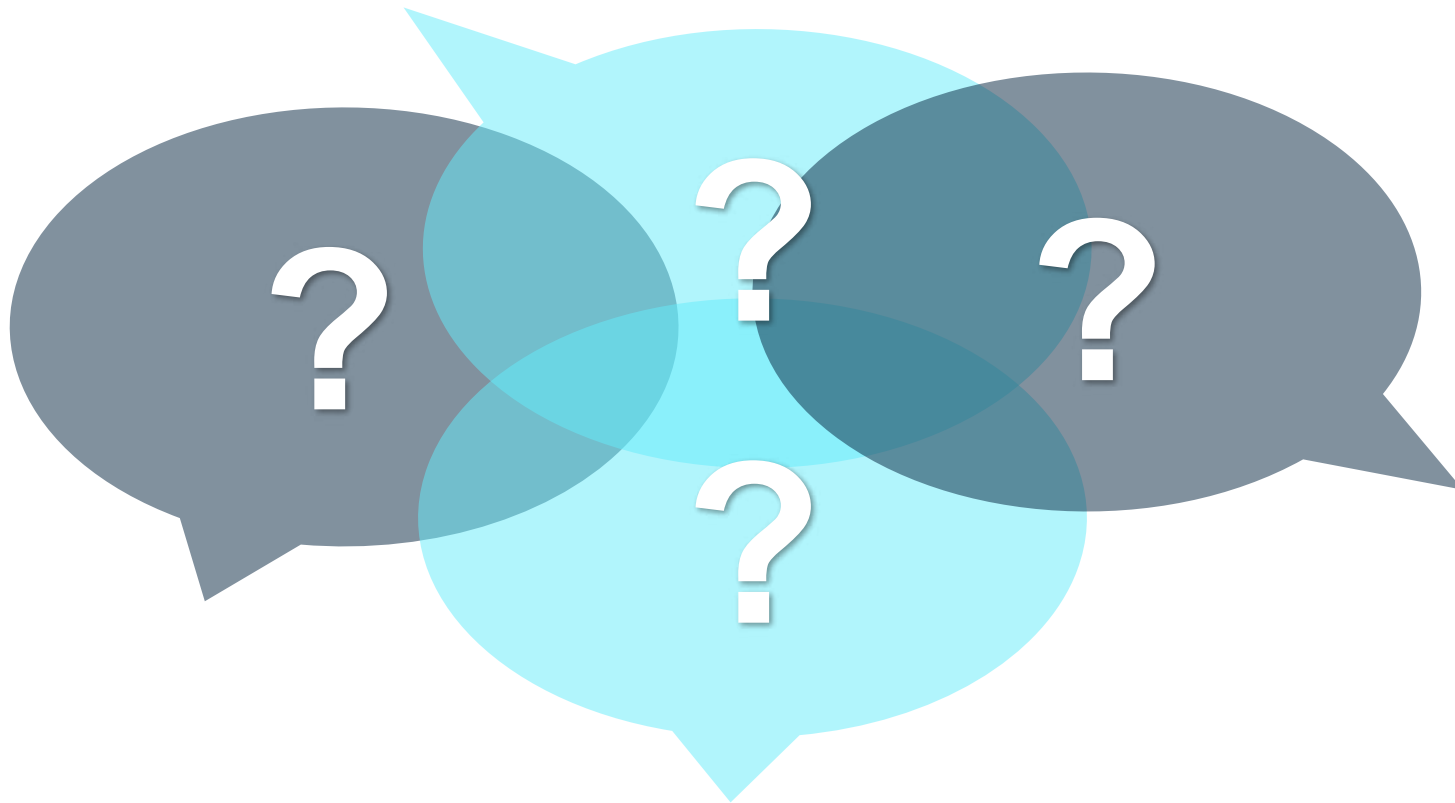
# What should be done?

- Make sure care homes included in pandemic planning
- Ensure all care homes (even irregular) can access:
  - Testing additional staff, PPE, medical support, additional isolation capacity, IPC guidance and training
- Work on making family visits safe
- Monitor impact of measures on people living with dementia
- [http://www.euro.who.int/data/assets/pdf\\_file/0004/443605/Tech-guidance-6-COVID19-eng.pdf?ua=1](http://www.euro.who.int/data/assets/pdf_file/0004/443605/Tech-guidance-6-COVID19-eng.pdf?ua=1)

## POLICY OBJECTIVES FOR PREVENTING AND MANAGING COVID-19 IN LONG TERM CARE (LTC)



# Question and answer



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# Lyn Rogers

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Person living with dementia  
Based in Victoria, Australia



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# Philip Connaughton

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Carer

Based in Ireland



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# Martin Jones

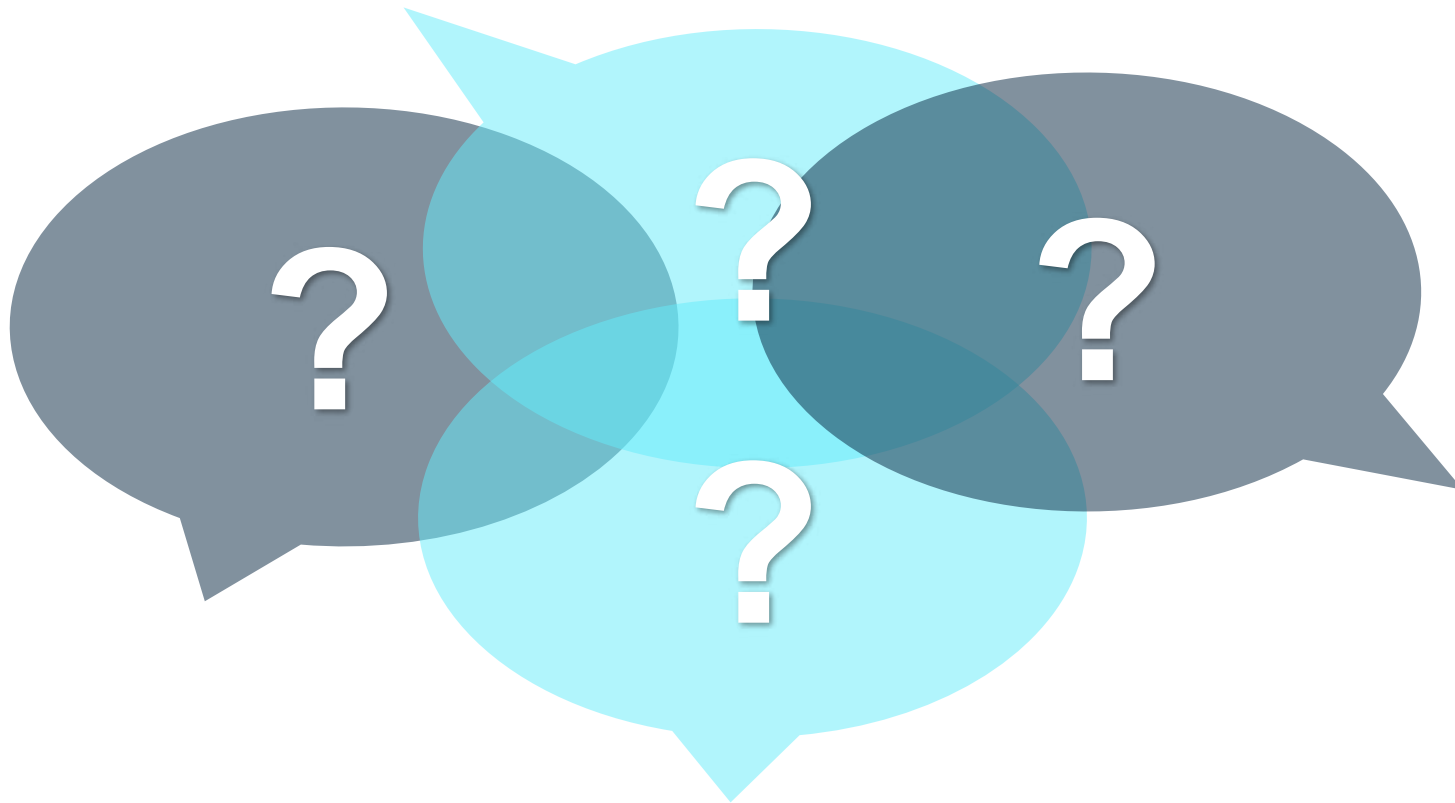
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CEO, Home Instead Senior Care  
UK



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# Question and answer



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## Saskia Sivananthan

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Chief Research & KTE Officer,  
Alzheimer Society of Canada  
Co-lead of the COVID-19 and  
Dementia Task Force in Canada  
Former senior strategy and policy  
advisor consulting for the WHO on  
its overall global dementia strategy



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# Canadian Perspective: A policy response to COVID-19 and Dementia

Dr. Saskia Sivananthan  
ASC Chief Research & KTE Officer



## Key Considerations

- Long-term care is not included under the Canada Health Act and, therefore, is not available to Canadians on a universal basis
- Programs, and therefore policies, including the response to COVID-19 vary by jurisdiction
- Programs are primarily income-based

# **Alzheimer Society of Canada COVID-19 & Dementia Task Force**

Rapid response team of leading researchers, clinicians, dementia specialists and people living with dementia from across the country

Mandate is to identify immediate gaps exposed in the healthcare system AND develop solutions

1. Intensive Care Practices Towards People with Dementia
2. Telehealth Assessments & Related Neuropsychological Tests
3. Impact on Infection Rate, Use of Health & Social Services in LTC and the Community
4. Long Term Care Impact
  - Best practices related to end of life care for people with dementia
  - Strategies for Human Connectedness in LTC
  - Strategies to support nursing home staff during COVID-19
5. Support for Caregivers of People with Dementia in the Community

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CANADIAN GERIATRICS SOCIETY  
LA SOCIÉTÉ CANADIENNE DE GÉRIATRIE



Dementia  
Advocacy  
Canada

*Voices of Lived Experience*



# Policies currently implemented

- Restricting all non-essential visits
  - Essential staff only, now some easing to allow friends and family
- Addressing shortage of staffing capacity
  - Temporary emergency orders to meet capacity needs
  - Military personnel deployed in some provinces
- Reduce spread between care settings
  - Restrict employment of healthcare workers to a single home

Source: Hsu AT *et al.* Report: Understanding the impact of COVID-19 on residents of Canada's long-term care homes — ongoing challenges and policy responses. Article in LTCcovid.org



# Reminiscence Activity



**Wendy Weidner**

Research and Policy Project Lead,  
Alzheimer's Disease International (ADI)



# Alison Dawson

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Senior Research Fellow, Faculty  
of Social Sciences, University of  
Stirling

Co-Leader of the Faculty's  
Dementia and Ageing Research  
Group



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# Care home design: impact and limitations during COVID-19

- Promotes and enables activity and interaction
- Provides privacy and preserves dignity in care



- Reduces stress through creation of familiar-feeling and calming environments

Alison Dawson, University of Stirling

Email: [a.s.f.dawson@stir.ac.uk](mailto:a.s.f.dawson@stir.ac.uk)

The Dementia Services Development Centre (DSDC): <https://dementia.stir.ac.uk/>

**BE THE DIFFERENCE**



# Care home design: impact and limitations during COVID-19



- Risk of disease transmission and challenges of infection control, especially in shared spaces





# Care home design: balancing COVID-19 risk and quality of life

**‘Recommendation 8:** Care homes should consider whether it is feasible to manage residents entirely within their rooms during the COVID pandemic. This will have implications for safe staffing, which should be considered before adopting such a policy.’  
*British Geriatrics Society (BGS) (2020)*

‘Social isolation and loneliness increases older people’s risk of anxiety, depression, cognitive disfunction, heart disease and mortality.’  
*Brooke and Jackson (2020)*

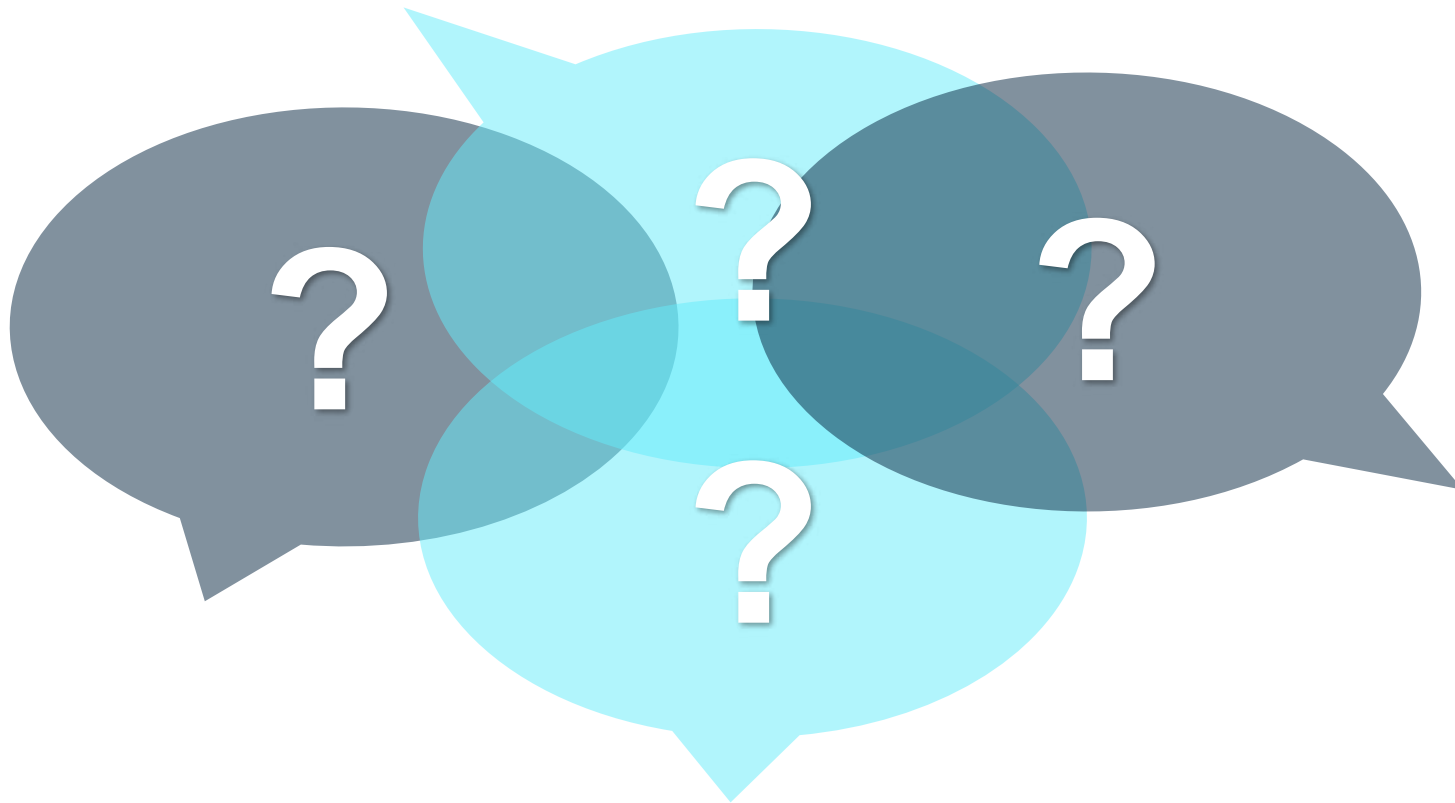
‘Care homes are residents’ homes. Restricting movement represents a significant loss of autonomy, with psychological and physical harms associated with social isolation and immobility.’  
*Gordon et al (2020)*

BGS (2020) ‘Managing the COVID-19 pandemic in care homes for older people. GOOD PRACTICE GUIDE’, updated 14 April 2020.  
<https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes>

Brooke J and Jackson D (2020) ‘Older people and COVID-19: Isolation, risk and ageism’, *Journal of Clinical Nursing*,  
<https://onlinelibrary.wiley.com/doi/epdf/10.1111/jocn.15274>

Gordon A, Goodman C, Achterberg W, Barker RO, Burns E, Hanratty B, Martin FC, Meyer J, O’Neill D, Schols J, Spilsbury K (2020) ‘Commentary: COVID in care homes—challenges and dilemmas in healthcare delivery’, *Age and Ageing*, , afaa113, <https://doi.org/10.1093/ageing/afaa113>

# Question and answer



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# Meera Pattabiraman

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Chair, Alzheimer's & Related  
Disorders Society of India  
(ARDSI)

Board Member, ADI

Member, World Dementia Council



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ARDSI. REMEMBER THOSE  
WHO CANNOT REMEMBER

अलजाइमरस एण्ड रिलेटेड डिसिऑर्डरस सोसाइटी ऑफ इंडिया  
**ALZHEIMER'S & RELATED DISORDERS SOCIETY OF INDIA**



**Alzheimer's Disease  
International**

# COVID-19 and the Dementia day-care scenario in India

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**Meera Pattabiraman, Chairperson ARDSI**

# Challenges and Initiatives taken by Day Care Centers run by ARDSI and Chapters

## Person with dementia

- **Challenges**

As their routine of visiting the daycare centre has been halted, they seem to be facing a lot of confusion, restlessness and boredom which is further leading to the manifestation of Behaviour and psychological symptoms in dementia ( BPSD)

- **Initiatives**

Distance mode of supportive services are ensured by Mumbai, Kolkata, Delhi, Hyderabad, Guwahati chapters and Kerala based services by National office and chapters. Video calls are held with persons with dementia in order to engage them with cognitive stimulating activities and to help them keep occupied in meaningful activities, which helps in managing BPSD

## Family caregivers

- **Challenges**

- Caregivers are stressed as they are unable to get any respite themselves. Facing difficulties managing household chores and providing round the clock dementia care during lockdown. As a result, anxious and worried about managing a possible emergency.

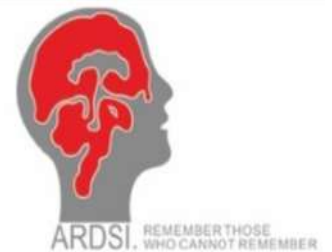
- **Initiatives**

ARDSI has developed roasters as per the staff and families' convenience to provide one on one counselling for family caregivers who seek support and are linked with other related support systems like Senior citizen helplines, emergency support, official announcements etc.

- ❖ Educating family caregivers on various protective measures (linked to hand washing, coughing, distancing, isolation and lockdown) and to obtain necessary support during this difficult time

# Governmental Directives to Support Elderly

- No Government directives have been made with respect to Dementia specifically
- The Indian government has provided a health advisory for the elderly population during the pandemic
- **Ministry of Electronics and Information Technology** has developed the **AarogyaSetu App**, 'It' is a mobile application developed by the **Government of India** to connect essential health services with the people of India in our combined fight against COVID-19.
- **The Ministry of Social Justice and Empowerment, Government of India** has issued comprehensive guidelines to States/Union Territories for the protection of persons with disabilities.
- **Helplines for senior citizens** and persons with disabilities established
- Provision of essential items to elderly under the Senior Citizen Cell in Kerala.





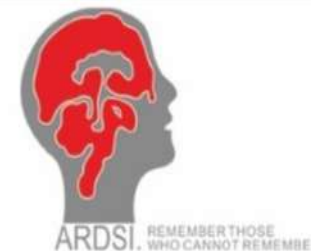
# Will Dementia Day-care come back in India?

**Of course the day care centers will reopen when the restrictions are lifted**

- Daycare will come back in time as all other services will after the curve is down
  - ❖ The day care centre at Cochi has started functioning
  - ❖ The Kolkata and Hyderabad day care centres will reopen as soon as the restrictions are lifted
    - 40% of caregivers in Kolkata felt that they will wait for a month to send, 50 % are willing to send if all precautions and protocols are followed and 10% of clients will no longer be able to attend as their health has deteriorated during the lockdown.
- ARDSI is developing effective ways to manage the risk of living with COVID- 19
- ARDSI aims to continue providing the valuable support and services in the future with adequate preparations like access/ availability of protective gears, access to essential medicines and disinfectants, and reliable information on their appropriate use
- We also aim to make COVID testing opportunities available for people with dementia, their family members and staff.

*“Of course I will send my Mother-in-law to the daycare as soon as it resumes, that was her only social interaction and activity”*  
- Primary caregiver, Daughter in law (Hyderabad)

*“That was my only respite time and support”*  
- Primary caregiver, Husband (Delhi) services



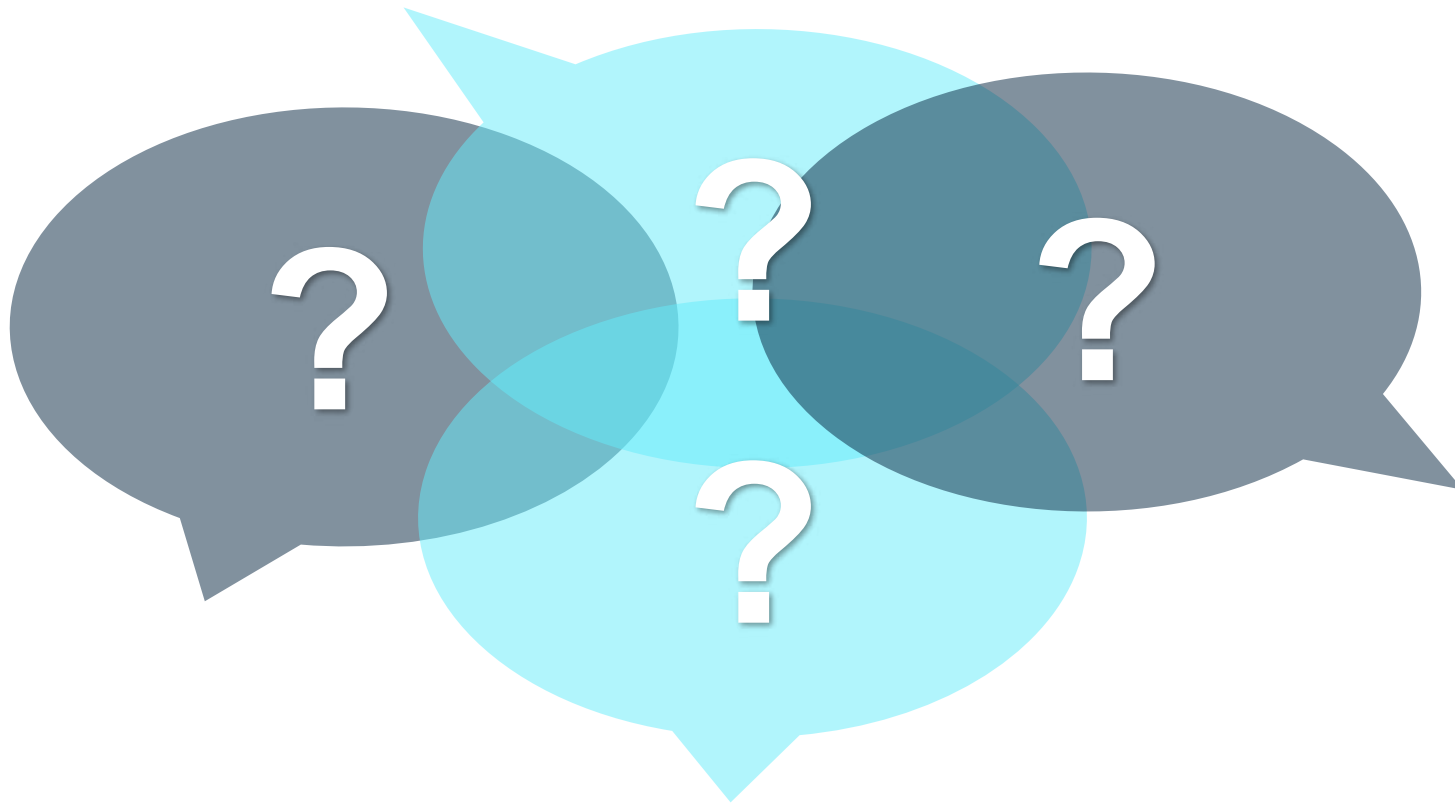
- Caregivers have expressed their trust in the centers to take all COVID-19 related safety protocols on resuming services

# Thank you

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# Question and answer



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# Closing Remarks



**Paola Barbarino**

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