ADi Response to COVID-19

The impact of COVID-19 on people affected by dementia and the global NGO response

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About Alzheimer’s Disease International (ADI)

• Established in 1984
• The umbrella organisation of Alzheimer associations around the world
• 102 member associations & federations
• Publisher of the World Alzheimer Report and promoter of World Alzheimer’s Month and Day
• Official Relations with WHO

Our vision is prevention, care and inclusion today, and cure tomorrow
3 points for today

• ADI’s COVID-19 response and key role of Alzheimer associations

• Emerging themes and concerns

• Where do we go from here?
Our motivation: future focus

We were concerned that:

1. Our constituency was at risk
2. That there was not enough information on practical issues
3. That governments would deprioritise dementia after all returned to normality
**ADI’s response to COVID-19**

<table>
<thead>
<tr>
<th>General resources</th>
<th>Resources for carers and people with dementia</th>
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<td>Additional support for Alzheimer's &amp; dementia organisations</td>
<td>Resources from Alzheimer and dementia associations</td>
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<td>Mental health and well-being</td>
<td>Videos</td>
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<td>Information and support for refugees, BAME, indigenous &amp; other marginalised groups</td>
<td>Resources in English, Spanish, Portuguese, Arabic, Greek</td>
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ADI’s response to COVID-19

- ADC presentation (English): Almost 10k views

- Publication of a Lancet article 'Dementia care during COVID-19' by Huali Wang, Paola Barbarino, Serge Gauthier et al.
COVID-19 and dementia webinars: Members

- Maintaining services during a crisis: How to continue supporting people with dementia and their carers
- Mental Health and Wellbeing during self-isolation
- Discrimination against Elders
- Positivity Forum
Association response to crisis: Innovation & devotion

• Information/guidelines – families, professionals

• Awareness raising – public and government

• Practical tips – hygiene, infection control, masks

• Innovative virtual support – music, dancing, exercise, carers groups, and telephone

• Helplines 24/7 – even personal phones

• Lifesaving support – access to doctors, shopping, medication

• Advocacy for human rights, protection from penalties

• Support for carers – social media support groups, physical and mental wellness tips e.g. aerobics
ADI’s response to COVID-19: Recognising difficult decisions and risk of ageism

"We are living through unprecedented times, but one thing is clear: ADI’s natural constituency, people affected by dementia and their families, are amongst the hardest hit. We have a global network and it has been natural for our members to collaborate through this crisis, show solidarity and work together. But we have also learnt that there are hard truths that we all need to face. This is the spirit in which we have reengineered ADI to be at the forefront in providing guidance, evidence-based information and cohesion through these difficult times. Our aim is to help you understand the impact on our community as events unfold and take better and more informed decisions. Stay safe." - Paola Barbarino, Chief Executive of Alzheimer's Disease International (ADI)

COVID-19 and dementia: Difficult decisions about hospital admission and triage

COVID-19 is a new viral infection that presents an unprecedented problem for everyone, including people with dementia and their families and carers worldwide. Although the scale and impact of COVID-19 varies from country to country, at an individual level, people affected by dementia and their families and carers are having to cope with rapidly changing information and guidance at a time when they have been asked to isolate from their regular support systems in the wider community.

Age, dementia and the allocation of health resources during and beyond COVID-19

Dr Linda Barclay, Department of Philosophy, Monash University and Glenn Reeves, Chair of Alzheimer's Disease International

The extraordinary circumstances of the COVID-19 pandemic bring into sharp focus a facet of life that most of us ignore: that health care resources are always limited. This is very true for people with dementia and more generally for people with disabilities. They are limited by political and economic decisions concerning expenditure on medical research, drug subsidies, health care funding and so on. These long-term issues will not be resolved in mid-crisis, but they are relevant to the way the crisis is handled. It is an opportunity to draw attention to longstanding issues and not give up in despair.

This article explores issues in health resource allocation, measurement of quality of life, the options open to decision makers and the importance of transparency in decision-making. There is no simple answer to complex decision making but the clear requirement is for transparent decision making in judgements that impact on people’s lives. The need goes beyond guidelines that are understood and acceptable to doctors and consumers and relevant in times of crisis at the bedside to broader issues of health policy, structural and legal issues.
COVID-19 and dementia webinars: Public facing

Supporting people with dementia during COVID-19

Future gazing

The hidden casualties of COVID-19
<table>
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<th>Major concerns for people living with dementia &amp; carers</th>
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<tr>
<td><strong>1.</strong> Excess dementia mortality in long-term care facilities, in hospitals, and at home, data still coming in</td>
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<td><strong>2.</strong> Triage guidelines must not be used in discriminatory way</td>
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<td><strong>3.</strong> Diagnosis rates for dementia have decreased during the outbreak – impact on cognitive decline</td>
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<td><strong>4.</strong> Psychosocial support for both people with dementia and carers</td>
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<td><strong>5.</strong> Palliative and end of life care must be supported, including at home</td>
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WHO’s Global action plan on dementia

Real concern that the progress made under the Global plan will be reversed by COVID-19 on the national and international level.
COVID-19 and dementia: what next?

- This is still not over: we need to listen, learn and understand
- Harness innovation – new technologies & ways of working, new partnerships
- Encourage continued openness, e.g. research and regulators
- Strengthen coalitions and work together on complex issues
- Use this moment in time as an opportunity to advocate for lasting policy change – new world, new policy, better care
THANK YOU.

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Email: w.weidner@alz.co.uk
Twitter @WeidnerWendy