World Alzheimer Report 2020
Design, dignity and dementia; dementia-related design and the built environment
Welcome & Introductions

Paola Barbarino
CEO,
Alzheimer’s Disease International (ADI)

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Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

10-12 December 2020
VIRTUAL CONFERENCE
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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https://www.alz.co.uk/donate
We are interested in learning more about you
Speakers

- Professor Richard Fleming, report lead
- Dr. John Zeisel, report co-lead
- Kirsty Bennett, report co-lead
- Kate Swaffer – CEO, Dementia Alliance International
- Kevin Charras, Ph.D - Centre Hospitalier Universitaire de Rennes
- Wilhelmina Hoffman, M.D., Silviahemmet
- Dr. Ishtar Govia, STRiDE Jamaica
- Dr. Alison Dawson, University of Stirling
Professor Richard Fleming

Professorial Fellow, Faculty of Science Medicine and Health, University of Wollongong

Executive Director, Dementia Training Australia
Principles, context and recommendations

Professor Richard Fleming
In comparison with many other fields, designing for people living with dementia does not have a large knowledge base.

Nevertheless, there is a sufficient range of views and isolated ‘facts’ that writing a report on the field would be made much easier if the contributors could, by and large, agree to use a small set of principles of design to structure their thoughts and writing.
In comparison with many other fields, designing for people living with dementia does not have a large knowledge base.

Nevertheless, there is a sufficient range of views and isolated ‘facts’ that writing a report on the field would be made much easier if the contributors could, by and large, agree to use a small set of principles of design to structure their thoughts and writing.
The extent to which designing specifically for people living with dementia is taking place around the world has not, to this point, been explored. The writing of this report provided an opportunity to begin this exploration and resulted in 84 case studies from 27 countries being identified.
There has been progress, but much remains to be done and it needs to be done with careful consideration of context and the overarching goal of affording dignity to people living with dementia.

Recommendations

1. Common set of design principles
2. Inclusion in National Dementia Plans
3. Work with advocacy groups to promote dementia as a disability and the adoption of dementia design guidelines
4. Include designing for people living with dementia in the curricula of schools of architecture and design
5. Encourage health economists to collaborate with designers on investigating the costs and benefits of supporting people with dementia to live in their communities.
6. Encourage the translation of knowledge
7. Encourage National Dementia Associations to promote the use of the available knowledge
8. Encourage governments to be proactive in engaging architects, operators and other key stakeholders in designing for people living with dementia
Dr. John Zeisel

President & Co-Founder of Hearthstone Alzheimer Care, Ltd.
Groundbreakers
Past, Present, & Interviews

Dr. John Zeisel
Co-lead World Alzheimer’s Report 2020
Little did we know then

- In the 1970’s & 1980’s
- Professionals in social & psychological sciences and in design
- Had no idea that dementia would grow into the worldwide challenge it presents today

- Mini Mental State Exam (MMSE) – Folstein
- Global Deterioration Scale (GDS) – Reisberg
- Environmental Psychology – Proshansky
- EDRA – Environmental Design Research Association
- Design for Dementia becomes a field of study
# Groundbreaking Projects 1978-1998

<table>
<thead>
<tr>
<th>Year</th>
<th>Groundbreaking Paradigm Shifters</th>
<th>Principles &amp; approaches the designers / operators explored in this environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1978</td>
<td>Le Cantou, Rueil-Malmaison, France</td>
<td>Separate small apartment in larger building, continued family involvement</td>
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<tr>
<td>1984</td>
<td>Aldersgate, Felixstowe, SA, Australia</td>
<td>Process innovation; non-institutional quality; redundant cuing</td>
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<tr>
<td>1987</td>
<td>Pepper Tree Lodge, Queanbeyan, AU</td>
<td>Unit for the Confused and Disturbed Elderly (CADE) broke Australia’s institutional model</td>
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<tr>
<td>1989</td>
<td>Anton Pieckhofje, Haarlem, NL</td>
<td>‘Family scale”, central services, differentiated style management</td>
</tr>
<tr>
<td>1991</td>
<td>Adards, Warrane, Tasmania</td>
<td>Homelike, accordion design to switch between “family” &amp; “community” scale”, lively garden</td>
</tr>
<tr>
<td>1991</td>
<td>Woodside Place, Pennsylvania USA</td>
<td>Neighborhoods with joint common space, family scale gardens, innovative details</td>
</tr>
<tr>
<td>1995</td>
<td>Hearthstone, Massachusetts USA</td>
<td>“Community scale,” central garden, engagement activities at “family” scale</td>
</tr>
<tr>
<td>1996</td>
<td>Himawari, Ofenatu Japan</td>
<td>First “family scale” in Japan</td>
</tr>
<tr>
<td>1997</td>
<td>Moorside, Winchester UK</td>
<td>Choice through design, unobtrusive care, Seeing and being seen</td>
</tr>
<tr>
<td>1998</td>
<td>Hasselknuten, Sweden</td>
<td>In town location, common areas open to the public, normalized life</td>
</tr>
</tbody>
</table>
Approaches discovered
today common sense / then groundbreaking

• Location in the community
• Family scale neighborhoods,
• Homelike & non-institutional
• Community scale commons
• Public invited into the Bistro
• Gardens full of life
• Engagement all day long

• Redundant cueing
• Resident choice by design
• Naturally mapped
• Seeing and being seen
• Community scale
• Stable staff
• Care that fits into life
Living groundbreaker interviews

### Pioneers
- Margaret Calkins – *Architect, Pioneer Researcher*
- Clare Cooper-Marcus – *Pioneer Garden Guru*

### Innovative architects
- Allen Kong – *Multi-Cultural Architect*
- Peter Phippen – *Groundbreaking architect & Innovator*
- Michael Murphy – *International Design Thinker*

### Paradigm Shifters
- Jannette Spiering – *Serial Innovator*
- Wilhelmina Hoffman – *Geriatrician-Designer-Innovator*
- Alan Dilani – *Salutogenic Champion*
The Interviews

World Alzheimer Report 2020
Design, Dignity, Dementia:
Dementia-related design and the built environment

https://www.alz.co.uk/research/world-report-2020
Kirsty Bennett

Senior Academic Consultant, Environments, Dementia Training Australia, University of Wollongong

FRAIA Architect Australia
Cultural aspects of designing for people living with dementia

Kirsty Bennett Architect FRAIA
Co-lead World Alzheimer Report
Cultural aspects of designing for people living with dementia

- Four domains (overarching goals, principles, approaches, responses)
- Principles the key in responding to culture
- Importance of context
- Focus on briefing
- Allow time
Cultural aspects of designing for people living with dementia
Cultural aspects of designing for people living with dementia
Education and training

• Report show cases well developed approaches
• In aged care organizations, universities, and companies
• Australia, Japan, Singapore, Canada, USA, UK
• Essential part of knowledge translation
• Include education in the curricula of schools of architecture and design.
Kate Swaffer

Chair, CEO and Co-Founder, Dementia Alliance International (DAI)

Board Member, ADI
Disability Rights, Enabling Design and Dementia

Kate Swaffer
MSc, BPsysch, BA, Retired nurse
Chair, CEO & Co-founder, DAI
Board member, ADI

@KateSwaffer
@DementiaAllianc
Reframing Dementia as a disAbility

Dementia is a major cause of disability and dependency among older people worldwide.

World Health Organisation, 2019, Dementia Factsheets, https://www.who.int/news-room/fact-sheets/detail/dementia

@KateSwaffer
@DementiaAllianc

Support and Advocacy, of, by and for people with dementia
• Even though people with dementia still retain the same rights as anyone else in society, including human rights and disability rights, there has been little change in the realisation of these rights;

• No longer can we pick and choose what rights we wish to uphold, or only focus on e.g. rights to dignity or health, which when interpreted do not disrupt the current medicalised approach to dementia;

• Disability Rights Matter to everyone.
The built environment and disability

- The environment’s influence in creating disability or in increasing it has been well established;
- It is seen as integral to the definition of disability;
- When the built environment changes, then the experience of someone living with a disability will also change.

@KateSwaffer
@DementiaAllianc
Thank you

We must all work towards ensuring the built environment for people with dementia is accessible.

We don’t need more reports or more rhetoric.

We need ACTION! Now!
Kevin Charras, PhD

Living Lab Vieillissement & Vulnérabilités, Service de Gériatrie, Centre Hospitalier Universitaire de Rennes, France
Human Rights, design and dementia: Moving towards an inclusive approach

Kevin Charras, Ph.D
Living lab Vieillissement et Vulnérabilité
CHU de Rennes
Human right based approach of design

Fighting injustice

Promoting competencies
Spaces and **settings** are cues of social and societal representations and **attitudes**

- **Common belief**
  - that people with dementia should be contained in **specific environments** and continuously under surveillance

- **Stigmatisation**, Self-depreciation, Segregation

- **Triggering maladapted behavioural schemes**
  - linked to deficiencies $\rightarrow$ Self-fulfilling prophecies
Dementia design induced stigmas
Advances in research on design and dementia

Equality
Therapeutic environments
Healing behavioural and psychological symptoms

Equity
Ergonomic/friendly environments
Compensating cognitive deficits
Inclusive design is a challenge for architects, designers and dementia care stakeholders.

- Social and spatial inclusion
- Empowerment: Promoting capabilities
- Removing barriers to promote generic and supportive environments
- Legibility & Affordances to address use of space and activate adapted behaviours and competencies
- Freedom, Independence, Choice, Dignity
People with dementia also have the right to age in place

- Maintaining independence and autonomy
- Connecting to social support, networks, and community
- Encountering cultural, generational and human diversity

Addressing social health issues:
- (1) capacity to fulfil potential and obligations;
- (2) ability to manage life with some degree of independence;
- (3) participation in social activities.

Inclusive design should prompt and be prompted by social and societal inclusiveness.
Wilhelmina Hoffman, M.D.

Principal and CEO, Stiftelsen Silviahemmet

President, national competence centre for dementia in Sweden ‘The Swedish Dementia Centre’
The foundation
Stiftelsen Silviahemmet
Dementia - Education and Care for Quality Of Life since 1996

Photo: Yanan Li
The idea of SilviaBo started with a cup of tea

www.silviahemmet.se
SilviaBo

A cooperation between knowhow about dementia
- Silviahemmet, housebuilding - BoKlok and IKEA

www.silviahemmet.se
Dr. Ishtar Govia

Strengthening Responses to Dementia in Developing Countries (STRiDE) Jamaica Project Lead

Lecturer, Caribbean Institute for Health Research (CAIHR) – Epidemiology Research Unit, The University of the West Indies, Mona Campus
Dementia, Design and Development: Approaches and Recommendations from STRiDE Countries

Presenter: Ishtar Govia, Ph.D., M.T.S, M.A.
STRiDE Jamaica Project Lead & Chapter Lead

Monday 21 September 2020, 13:00 p.m. - 14:15 pm (BST)

stride.dementia@lse.ac.uk
Diversity & Choice
Challenges in LMICs in Designing for Dementia

- Most care homes privately-operated and costly
- The average older person in a LMIC does not belong to a high-income group
- Lack of awareness and systems to safeguard persons with dementia
- Existing environmental challenges
- Dementia not seen as a national priority
- Presence of stigma (further exacerbated by COVID-19)
Key Findings & Recommendations for Designing for Dementia in LMICs

Safety is a top priority in all contexts and is a family responsibility in LMICS.

Cultural adaptation to application of principles is a must.

Design principles are not feasible in some contexts.

Care home site: India
Key Findings & Recommendations for Designing for Dementia in LMICs

Creative solutions occur in low-resourced settings

Dementia is an issue in LTC and should be incorporated in other policies in LMICs

Assumptions of the principles need to be adjusted in low-resourced contexts
From the co-authors: Thank you!

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Dr. Alison Dawson

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

Co-Leader of the Faculty's Dementia and Ageing Research Group
Lessons from COVID-19 and impacts on dementia design

Special thanks to:

Chris Lynch and colleagues at Alzheimer’s Disease International

Richard Fleming, John Zeisel and Kirsty Bennett, ADI World Report 2020 leads

Whitney Berta and Frances Morton-Chang, Institute of Health Policy, Management & Evaluation, Dalla Lana School of Public Health, University of Toronto

Lesley Palmer and Martin Quirke, Dementia Services Development Centre, University of Stirling

Alison Dawson, Faculty of Social Sciences, University of Stirling
Email: a.s.f.dawson@stir.ac.uk
The Dementia Services Development Centre (DSDC): https://dementia.stir.ac.uk/
Lessons from COVID-19

• We are all vulnerable
  

• We are learning but we still know very little
  
https://www.britannica.com/science/coronavirus-virus-group
Lessons from COVID-19

• Social and physical interaction are important

• Front-line workers are critical
Impact on dementia design

• Privilege design to meet clinical / medical needs

• Question whether dementia design can be ‘fit for purpose’

• Encourage invention and innovation
COVID-19 and design: a call to action

We must reach across academia, practice and lived experience and:

• Revisit dementia design principles
• Recognise rights and manage risks
• (Re-)design for context

https://www.alz.co.uk/research/world-report-2020
Question and answer
Closing remarks

Paola Barbarino
CEO, Alzheimer’s Disease International (ADI)
Hope In The Age Of Dementia.

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THANK YOU.

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