



The ‘New Dementia’: Widening Choices for People with Dementia.

A project of the Scottish Universities Insight Institute

Programme title	The ‘New Dementia’: Widening Choices for People with Dementia
Programme Team (Name, organisation)	People living with dementia: Dr. James McKillop MBE; Agnes Houston MBE; Anne Ramsay; Archie Noone Partners: Frank Ramsay Academics: Prof. Heather Wilkinson and Dr. Liz Taylor (ECRED), Prof. Mary Marshall and Dr. Julie Christie (HammondCare), Dr. Amanda Nioi, Alison Hamilton-Pryde and Dr. Sarah Payne (Heriot-Watt University) Facilitator: Philly Hare (Innovations in Dementia)

Summary

This project addresses an emerging and substantial issue facing Scotland and beyond in relation to suitable housing options for people with dementia who, mainly due to policy developments, have received an early diagnosis of dementia, and have now been living with dementia for five plus years. Some of these people have coined the phrase ‘the New Dementia’, because their experience defies dominant medical understandings of the middle stage of dementia. People in this group continue to lead active lives, and, while they do need support and may not be able to stay at home much longer, they are not ready to move to institutional-like care homes.

The work took place between April and September 2017. It aimed to support people with dementia, policy makers and other stakeholders in Scotland to learn from other countries, and each other, about alternative housing-withcare/care home models, through co-produced films, workshops and a briefing paper.

This work is innovative in that it addresses an emerging situation, works with people with dementia to find solutions, and seeks to learn from people with dementia in other countries where alternative housing-with-care/care home models are further advanced.



The aim of this project is twofold:

- to investigate alternative housing-with-care/care home models from overseas through experiential approaches, which enhance the meaningful involvement of people with dementia
- to facilitate cross-sector discussions on lessons to be taken from these models and applied to the Scottish context.

Our project challenges current models of accommodation for people with dementia in Scotland, by learning from Canada, Japan and Australia to build upon existing work. Subsequently, workshops engaging policy and care stakeholders and people with dementia were organised with hopes of influencing the future direction of developments. Building on the coproduction model of working in the Edinburgh Centre for Research on the Experience of Dementia (ECRED), and drawing on theories of citizenship (Bartlett and O'Connor, 2010), the project also challenges a traditional academic research approach by ensuring that the views and experiences of people with dementia are central in the sharing and development of knowledge.

What we did:

We focused on some key questions:

1. What do people living with dementia think of the alternative housing-with-care options used in other countries? Would they like similar options here? What are their reflections on current options in Scotland?

Through a process of co-production, we worked with people with dementia to bring their learning from Japan, Canada and Australia directly to those who have the power to influence change in policy and practice in relation to the provision of alternative housing-with-care models for people with dementia living in Scotland. A study group visited several options in Japan and spoke with people with dementia. A short film was made of this visit. Films and experiences from HammondCare in Australia were shared. Agnes Houston shared some of her views from a study tour of Canada. These different experiences were gathered and then shared in the first workshop. This form of experiential and international knowledge from people with dementia themselves has been a core contribution to the workshops and vital for the success of the project objectives.

On Friday 14 July 2017, several people affected by dementia (four living with dementia, plus one carer) met at the Festival Theatre in Edinburgh to discuss their hopes, fears and wishes about their futures - especially if that were to involve a move to some kind of supportive accommodation/care home.

As part of the facilitated discussion, the participants were shown brief presentations about options available overseas. Participants shared knowledge of small group living models of care from Australia and Japan, and of a retirement village model from Canada.



The examples:

Japan, with over 5 million people living with dementia, has developed innovative accommodation models which enable people with dementia to live as active citizens and remain connected within their communities. Japan now has over 12,000 state-funded dementia group homes.

Schlegel Villages offer residential living that combines quality long-term care with retirement villages across Ontario, Canada. They cite their defining features as: physical design, investment in people, integration with the larger community, and innovation. The design of the space creates a 'village' feel, with recognisable places such as Town Square and Main Street. The communities also provide a Town Hall, café and Community Centre. Integration with the larger surrounding communities is essential to the ethos of Schlegel Villages (see references).

HammondCare is an independent Christian charity specialising in dementia and the care of older people, palliative care and rehabilitation. They are one of Australia's most innovative health and care providers, delivering hospital and residential care and community services.

The presentations included:

- a short film, 'Learning from Japan', put together by Liz Taylor and Philly Hare, following a study tour of group homes in Japan earlier in 2017. (Created by VideoCake from images and conversations filmed by Taylor and Hare) (See link in references)
- James McKillop contributed from his previous visits to Japan.
- a presentation by Professor Mary Marshall, and a short film, 'Maria's story' (see link in references), about HammondCare 'cottages' in Australia. Agnes Houston also contributed from her visit to Australia in 2016.
- a presentation by Agnes Houston about her recent visit to Schlegel villages in Canada, using her Winston Churchill Travelling Fellowship.

These were presented not necessarily as models to be admired and copied, but to stimulate discussion.

A briefing paper has been co-produced with those participants through the process of two workshops. It aims to share the reflections of the group with key influencers in Scotland.

http://www.ed.ac.uk/files/atoms/files/widening_choices_suui_report_final.compressed.pdf

Attendees from the workshops, key policy makers, and other stakeholders in Scotland (e.g. from design, care and voluntary sectors) then met at a second event held on 20 September 2017. Here people engaged in discussions on future directions for Scotland, after video presentations and presentations from participants who had created the briefing paper.

The Briefing Paper covers the following main areas:

- Making decisions – and needing support to do so
- Choice
- Informality
- Freedom and risk



- Physical space and opportunities for quiet
- Who are small-group schemes for?
- End-of-life care

A key part of the discussions focused on ‘so what would we want?’ This identified a number of features that are important to them in any model of care, not a ‘wish-list’ but as a matter of “*our human rights, for example the right to a family life...*”.

The **six key features** are:

1. An informal, family feel, a “*sense of belonging.*” A non-regimented, non-institutional situation. Small units with “*a sense of love*”.
2. A positive culture, a feeling of “*helplessness-to-hopefulness*”.
3. The freedom “*to do what you want to do, when you want to do it.*” Reassurance of safety, but the perhaps the option to “*opt in or out of risk.*”
4. Well-trained staff (more important than the surroundings). Specifically, with skills and training in end-of-life care.
5. Quiet places to go - including access to outdoor space.
6. Flexible facilities. Different levels of care that you can move between (not have to leave). But non-segregation – not dementia-specific units. Facilities for couples (including same-sex).

What next?

This project raises questions and challenges that we would like those in a position of influence to consider. These include:

How can choice and decision-making be supported?

- Can there be a single place to get information about housing models and care home models that will meet the needs of people with dementia?
- How can people with dementia find out about the alternative models that *already* exist in Scotland
- Can these discussions be part of post-diagnostic support?
- Could there be a ‘one-stop shop’?
- Could someone be appointed to go with a person with dementia to look at places, especially if they are not local. No one area has all these options available?
- Should there be particular attention given to those living alone, or with an elderly or disabled partner?
- Could there be a glossary of terms and their meanings (care home; nursing home; extra care; housing with care; retirement community; village; assisted living; cottages; group homes)?



How can we understand better the priorities and aspirations of people living with dementia, and also of their families?

- How can people living with dementia today be supported to use their knowledge to advocate on behalf of their future selves?
- How can people with dementia be involved in the planning of new schemes from the very start?
- How can they continue to be involved as advocates within care homes?
- How can those living in care home settings be helped to ‘opt in or out of risk’?

How can planning for the future help us to meet these aspirations?

- Could the models we have discussed work in Scotland?
- Can providers, commissioners, planners take a closer look at other innovative alternatives to care homes, such as Shared Lives, co-housing, HomeShare etc.
- Can we look again at the *costs and benefits* of small group models of care?
- Is this model cheaper, or does it cost more? Can we afford *not* to innovate?
- Could young people be encouraged to spend a year working in care homes through a special high-status post-school scheme?

The last word

This work, with its international element, has stimulated interest in how we can be better informed about innovative care settings here in Scotland, and how we can best support people with dementia to plan for increasing care needs.

As one of the group put it:

“These examples from overseas help to show what we could aspire to in this country. But would we accept the cost?”

... and as another responded:

“But can we afford not to change things? The cost to the ‘human element’ could be more in the long run if we don’t. If it’s not working, let’s look through a different prism. We need choice.”



References

Bartlett, R. and O'Connor, D. (2010). *Broadening the Dementia Debate: Toward Social Citizenship*, Bristol, UK: The Policy Press.

Links:

<http://schlegelvillages.com/about>

<http://www.hammond.com.au/>

<https://vimeo.com/238834251/bc273adaf>

<https://www.youtube.com/watch?v=Rfo2RIRxnog>

Houston, A (2017) 'Think Dementia, Think Sensory' Booklet available at sensorychallenges.tk

<https://www.ed.ac.uk/health/research/e-cred/ecred-news/the-new-dementia-widening-choices>

Project team

People living with dementia: Dr. James McKillop MBE; Agnes Houston MBE; Anne Ramsay; Archie Noone

Partners: Frank Ramsay

Academics: Prof. Heather Wilkinson and Dr. Liz Taylor (ECRED, University of Edinburgh), Prof. Mary Marshall and Dr. Julie Christie (HammondCare), Dr. Amanda Nioi, Alison Hamilton-Pryde and Dr. Sarah Payne (Heriot-Watt University)

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About the contributors

Anne Ramsay, from Edinburgh, is a mother of two, who has travelled extensively. She is still coming to terms with her fairly recent diagnosis, and dealing with things day to day, but says she has more of a social life than before her diagnosis.

Frank Ramsay is Anne's husband. He worked in telephones and TV. Together they are thinking about whether or not they should move.

Agnes Houston MBE, from Coatbridge, is an ex-nurse (A&E and the Army), a wife and mother (of Donna). Her husband also has dementia. Agnes was diagnosed 11 years ago. She is happier living day to day, but she is also a person who needs to take responsibility for future planning.

Dr James McKillop is married with four children (one in Australia). He lives in Glasgow and had his diagnosis 17 years ago.



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Archie Noone, from Dundee, is a retired lecturer in anthropology and has also travelled a lot. Diagnosed 6 years ago, he now chairs SDWG. Archie says:

“Dementia is the best thing that has happened to me – I have met so many people.” His favourite saying is: “I have dementia... but dementia hasn’t got me.”