

FUNDED BY

NIHR | National Institute for
Health and Care Research



SUPPORTING PEOPLE LIVING WITH DEMENTIA IN ECH

Teresa Atkinson &
Rebecca Oatley
Association for Dementia
Studies



University
of Worcester
Association for
Dementia Studies



Housing & Home

We all want to live in the place we call home, with the people and things that we love, in communities where we look out for each other

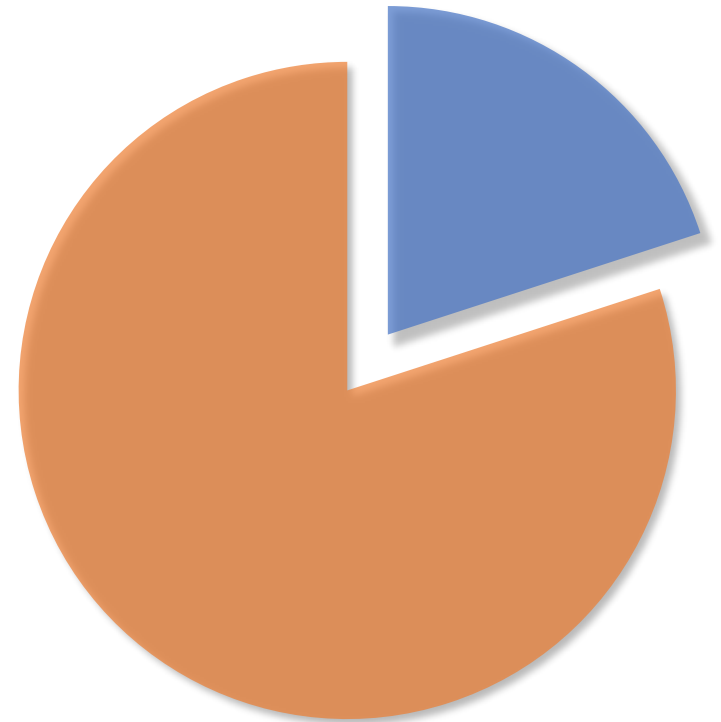
(Putting people at the heart of new housing development, ADASS 2022)

Every decision about care, is also a decision about housing

(APPG Report: Housing for people with dementia: Are We Ready? 2021)

People living with Dementia in ECH:

Over a fifth of residents in ECH are living with dementia, yet little is known little about how best to support people with dementia to live well in ECH.





**People with
& without
dementia**



**Just people with
dementia**



**People with dementia
live separately from
other residents**

The DemECH project

APPG Key Issue 19: The impacts of housing, ways of delivering interventions to support people living with dementia are under researched in the UK. Universities are starting to engage with research in these fields but research funding that specifies dementia and housing as a topic will encourage this further.

To explore how different models of ECH sustain wellbeing of people living with dementia

- Explore benefits & challenges of ECH for people with dementia
- Identify factors that impact upon benefits & challenges
- Explore advantages & disadvantages of different models





What did we do?

- Advisory Board
- Literature review
- Surveys & consultation including people living with dementia
- 100 Interviews at 8 different case study sites
- 100 participants (including 55 people living with dementia/family carers)

Enabling/Disabling Systems

Legislation

Policy

Economic climate

Commissioning model

Organisational priorities

Social opportunities

Staff

Other residents

Family/
friend support

Physical environment

Assistive technology

Resident living with dementia

Outcomes

Supported independence

Symptoms of dementia

Wellbeing

Physical & mental health

Chronosystem



Benefits of living in ECH

1. Flexible care and support provision focussed on supported independence
2. Sense of safety and security
3. Having your “own home”
4. Onsite organised/informal social opportunities
5. Age-friendly convenient living
6. Opportunity to continue to live together as a couple

What challenges are there to living well with dementia in ECH?

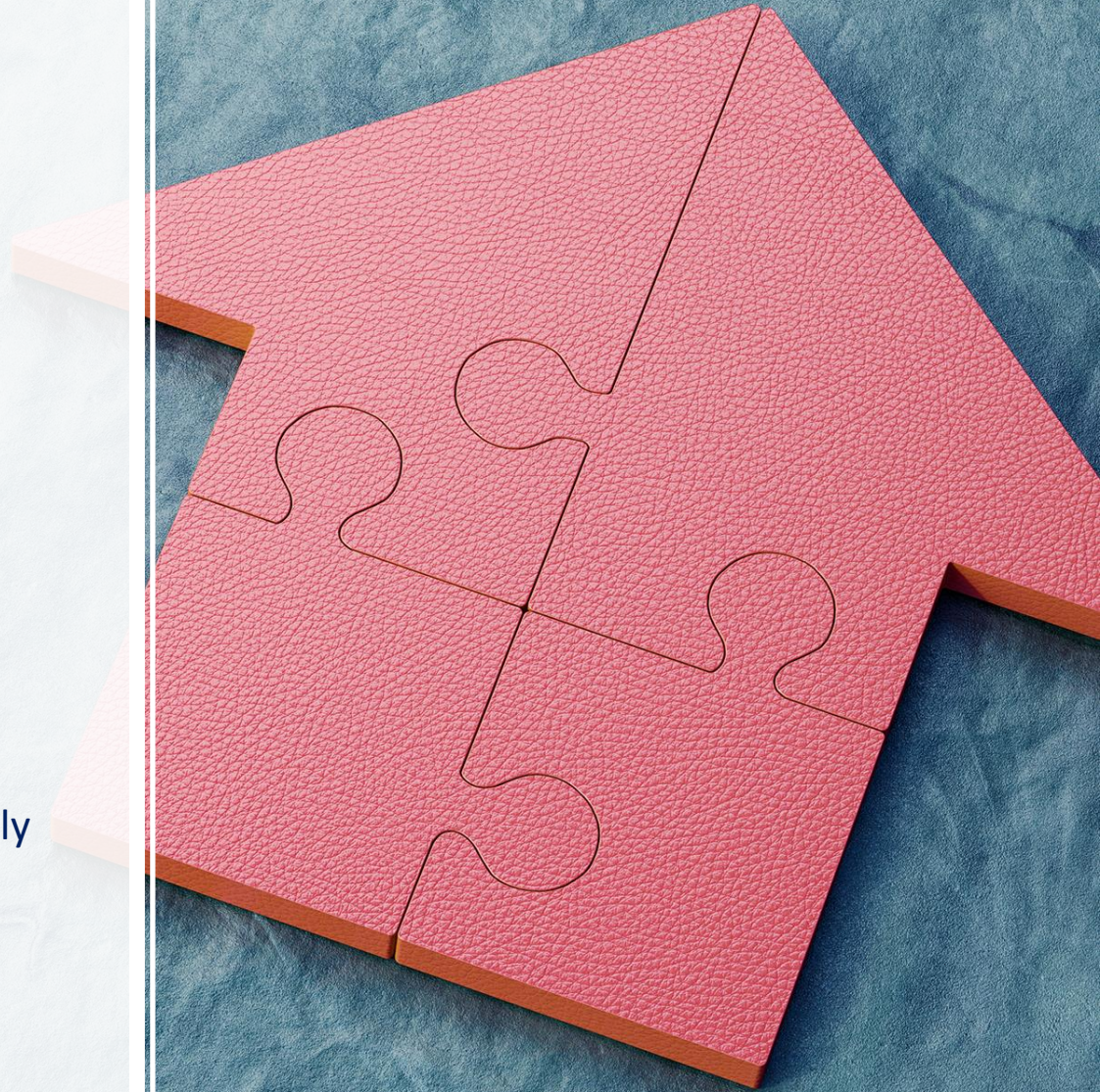
1. Lack of understanding over what ECH is
2. Familiarising self with new people, places & routines
3. Availability & accessibility of resources (including staff)
4. Privacy and the risk of loneliness
5. The stigma of dementia
6. Advancing symptoms of dementia

“Lonely.. That is the main thing”

Pat, living with dementia

What variables might impact whether it works well or not?

1. Individual personality and history
2. Symptoms of dementia
3. Level of family (or friend) support
4. Staff (culture of care, training, consistency of team, leadership, resourcing)
5. Availability of specialist dementia staff support or specialist social inclusion opportunity
6. Relationship(s) with other residents (and broader Dementia Friendly culture of the scheme)
7. Physical space & environment (e.g. facilities, size, design)
8. Model of scheme (integrated, specialist, separated)



What does this mean for people?

- Why are we here today?
- What do we want you to take away from today?



So what is the 'Extra'?

- The 'Extra' is not 'Extra' care.
- The 'Extra' is opportunities and reassurance that can enable a person (and family members) to live as well as possible. Ideally... support positive risk taking.
- *It is a combination of variables that must be balanced around the individual to promote their strengths and support their needs to optimise benefit of ECH for each person. There is no one size fits all.*

What do residents with dementia think ECH is?

“To me it simply means that I do have 24-hour backup, and someone comes to see me a couple of times a day and they do a little bit of washing up such as it is”

William, living with dementia

“I mean, they’re around if I get any problem at all. All I have got to do is call them”

Anne, living with dementia

“Life is a good thing when you help other people, chat with them and have a good laugh, basically”

Maureen, living with dementia

**Build your
networks:
Keep in
contact**

Website: www.worc.ac.uk/dementia

Email: dementia@worc.ac.uk

Join our mailing list:

www.worcester.ac.uk/ads-mailing-list

Follow us on Twitter and Facebook:



@DementiaStudies



@adsuow

This study/project is funded by the National Institute for Health Research (NIHR) School for Social Care Research 102645/ER/UWTA-P180. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.