



**Benefits and challenges of living in Extra Care Housing:
Perspectives of people living with dementia**

Journal:	<i>Working with Older People</i>
Manuscript ID	WWOP-09-2023-0035
Manuscript Type:	Research Paper
Keywords:	dementia, Extra Care Housing, Benefits, Challenges, Supported Living, Voice

SCHOLARONE™
Manuscripts

Title

Benefits and challenges of living in Extra Care Housing: Perspectives of people living with dementia

Structured Abstract

Purpose: The paper presents the views of people living with dementia in extra care housing. This is a model of housing with care and support aiming to support older people, including those with dementia to live independently. Previous research identifies benefits but is predominantly derived from third party accounts, with the voices of those living with dementia in extra care housing significantly absent.

Design/Methodology/Approach: The study adopted a qualitative approach conducting 100 interviews across 8 extra care housing schemes in England. Over half of the interviews were conducted with people living with dementia and their families with the remainder involving staff and commissioners.

Findings: Findings suggest there are a range of benefits including owning your own home, having a safe, age friendly location with flexible support, social interaction and continuing to live as a couple. Challenges included availability of staff, flexible resourcing, loneliness and the advancing symptoms of dementia.

Research limitations/Implications: Despite efforts to create an inclusive, diverse sample, the participants were all White British. Participants involved were identified by gatekeepers, which may present some bias in the selection.

Practical Implications: Whilst extra care housing offers benefits to people living with dementia, addressing the challenges is essential for effective dementia care. Improving staff training, promoting person-centred care, and fostering an inclusive community are critical for enhancing residents' well-being and quality of life.

Originality/value: This paper explored the lived experiences of residents and family members, providing new insight into the advantages and disadvantages of ECH for people living with dementia.

Keywords: Dementia, extra care housing, benefits, challenges, family carers, supported living

Article Type: Research paper

Introduction

Ageing in place has been a UK priority for some time (Sixsmith & Sixsmith, 2008) and a preference of our ageing communities (Pettersson et al, 2020), offering the opportunity for older people to remain in their own homes for as long as possible (Grimmer et al, 2015). However, there are greater challenges for people living with dementia (Hadjri, Rooney & Faith,

1
2
3 2015, Mawhorter, Wilkie & Ailshire, 2023) who face difficulties with remaining safe in their own
4 home as symptoms progress (Yin, Lin & Chen, 2023).
5
6

7
8 Appropriate housing is directly linked to health and quality of life (Feng et al, 2018; Garin et al,
9 2014; Government Office for Science, 2016; Iwarsson et al, 2007, Stewart et al, 2014) and can
10 significantly impact on wellbeing (World Health Organisation, 2018; Marmot, 2010). As a
11 sector which requires further development, a UK task force for older peoples' housing has now
12 been established to push this government priority forward (UK Government, 2023).
13
14
15

16
17 Extra Care Housing (ECH) is a model of purpose-built housing with on-site care and support
18 that is designed to support ageing in place (Oatley & Atkinson, 2023) . It provides people with
19 authentic choice between receiving domiciliary care in their own home and living in residential
20 care (Twyford, 2018). This model of housing with care has been purposely appointed to
21 provide the option for a person to lease or own their apartment, with flexible care provision
22 on site should it be required (Riseborough et al, 2015; Evans et al, 2017). Additional facilities
23 are often available such as café, restaurant, social activities, hairdresser, library, etc, although
24 these are dependent upon the size and locality of the scheme. An overriding feature of ECH is
25 its aim to support independence, autonomy and wellbeing amongst its residents by providing
26 a safe, secure and supported environment (Smith et al, 2022). Darton and Callaghan (2009)
27 report benefits for people living with dementia including less deterioration in cognitive and
28 physical functioning in comparison to people moving into care homes over the same period
29 of time. Benefits for the wider population include improvements in physical, psychological
30 and social well-being as well as health cost savings (Holland, 2015).
31
32
33
34
35
36
37
38
39
40
41
42

43
44 With the development of ECH spanning over 20 years (Atkinson et al, 2014) a number of
45 different models have emerged (Barrett, 2012). Integrated schemes are the dominant model
46 where people with little or no care needs live alongside people with a variety of different
47 conditions (Barrett, 2023; Twyford, 2016). Specialist schemes provide exclusively for people
48 with dementia , whilst separated schemes have made provision for this population in a
49 separate area of the scheme. Provision of different types of schemes varies by geographical
50 location and local authority commissioning models. People living with dementia account for
51 1 in 5 residents in ECH (Barrett, 2020) and may find themselves living in any of the different
52 models according to preference or availability of provision.
53
54
55
56
57
58
59
60

1
2
3 As a model of independent living, ECH, if it is to be considered a home for life, should be
4 capable of supporting residents to enjoy the benefits of a 'place to call home' (ADASS, 2022).
5 Series (2022) suggests there are different dimensions of 'home' including home as a haven;
6 home as territory; scaffolding for the self and the social home. Crowther (2022) proposes that
7 Series' analysis demonstrates the clear role of 'the place we call home' in constructing,
8 reaffirming, holding our personhood' and further notes that 'when these dimensions of what
9 makes home "home" are not upheld, it ceases to be a home' (p.24). Personhood is defined by
10 Kitwood (1997) as 'a standing or status that is bestowed upon one human being, by others, it
11 implied recognition, respect and trust' (p. 7). However, there is currently little evidence as to
12 what works best, and for whom, with regards to ECH and people living with dementia
13 (Anonymous), O'Malley & Croucher, 2005; Dutton, 2010; Twyford, 2016) and whether it can be
14 considered a 'home for life' (Kneale & Smith, 2013). Delivering person-centred care, having
15 staff expertise in dementia, flexible staffing, appropriate facilities and social activities, effective
16 design, partnership working and engagement with the wider community are all reported to be
17 important for supporting people living with dementia in ECH (Brooker et al., 2011; Evans et al.,
18 2020; Smith et al., 2022; Anonymous). However, the voices of people with dementia are often
19 absent from research (Bowers, 2009; Evans, Vallyelly & Croucher, 2014; Volkmer et al, 2023) with
20 evidence being offered through third party accounts. This study sought to put the voices of
21 people living with dementia, their spouses and other family members at the heart of the
22 enquiry to obtain insight into their perception of the benefits and challenges of living in ECH.
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42

43 **Methodology**

44 The paper reports on findings from a large project that explored the experience of living with
45 dementia in ECH. It was funded by the NIHR School for Social Care Research
46 (102645/ER/UWTA-P180) and ethical approval was granted by the Health Research Authority
47 (21/HRA/3769).
48
49
50
51
52

53 The focus of this paper is the following research question:

54 **What are the benefits and challenges of living with dementia in ECH?**

55 Semi-structured qualitative interviews were conducted with 100 participants across eight case
56 study sites (see Table 1 for details) Interviews took place face-to-face in a private room within
57
58
59
60

1
2
3 the scheme. External adult social care professionals were interviewed online using Microsoft
4 Teams.
5

6
7 ***[please insert Table 1 here]***
8

9 Case study sites were purposively selected to represent the diversity of size, facility, location
10 and models of ECH available (integrated, specialist, separated). Site identification occurred
11 through desktop research, the NIHR ENRICH network, and the project advisory group¹. Initial
12 intentions had been to recruit three sites per model, but only a single separated site was
13 identified (Scheme 7). A former separated site (Scheme 6) was also included as the transition
14 was relatively recent with a number of staff being retained following transition. Details of sites
15 identified are provided in Table 2. All schemes included social housing units.
16
17
18
19
20
21
22
23
24

25 ***[please insert Table 2 here]***
26

27 Senior staff members identified potential participants (residents, staff) at each scheme. For
28 residents with dementia, a process model of consent was used (Dewing, 2007). All participants
29 had capacity and provided written consent. However, had this not been the case, a consultee
30 process had been sanctioned by the ethics board. This was likely unnecessary due to
31 gatekeepers purposively selecting residents they believed had capacity to participate.
32 Interviews were recorded and transcribed, with any identifying details removed and replaced.
33
34
35
36
37

38 For data analysis, a template analysis approach was employed (Brooks et al., 2015; King, 2012).
39 An initial template was developed from early interview analysis. Coding and analysis were
40 carried out concurrently alongside additional data generation. Regular research team
41 meetings were held to refine the coding template, and coding examples were subjected to
42 discussion and enhancement with the advisory group. Data were coded within participant
43 categories across models and including both latent and semantic content.
44
45
46
47
48
49

50 **Findings**

51 Findings in this paper are presented as an overview of benefits and challenges of living with
52 dementia in ECH, irrespective of scheme type. A discussion of the relative benefits and
53 challenges of different models has been reported elsewhere (Anonymous). Themes are
54
55
56
57

58
59 ¹ The project advisory group was made up of professionals with expertise in housing, adult social care,
60 dementia and people with lived experience of dementia.

1
2
3 described with exemplar data, before a discussion of the relevance of the findings, limitations
4 of the study, and ramifications for practice and future research are presented.
5
6

7 Sources of quotations are made clear and [brackets] are used to clarify meaning or abbreviate
8 quotations. Resident spouse is used to identify that the person was living in ECH with a partner
9 with dementia.
10
11

12 **Benefits**

13 **Owning your own home**

14 Residents in this study described that it was important to feel a sense of ownership over their
15 own home:
16
17

18 *"I've got a big space you see, all this is mine."* (Edith, resident with dementia, Scheme 2)
19
20

21 *"I come in it and it's all mine. I can walk to the front door, lock it up and that's it."* (Frank,
22 resident with dementia, Scheme 8)
23
24

25 Having ownership was important for a sense of identity, familiarity, and stability:
26
27

28 *"[It is important to have my own stuff]. It's mine, and I look after things."* (Laura, resident
29 with dementia, Scheme 2)
30
31

32 *"This table for instance, I love, because I can hold onto it, and it doesn't move, like most
33 other things in life do. So, I just grab hold of this when I feel the need"* (Edith, resident
34 with dementia, Scheme 2)
35
36

37 Personal possessions could also stimulate positive memories and reminiscence:
38
39

40 *"[The furniture is important] because looking at different things, like the bookcase, my
41 husband and I went together to buy that, so that makes that quite personal"* (Sheila,
42 resident with dementia, Scheme 1)
43
44

45 *"I've got an army photo over here, and people come in and they pick that up
46 straightaway, 'oh yeah, you was there?' It's nice when they've never had to do it. We
47 used to do two years, or near enough three years in the army, you'd go from Germany to
48 Cyprus, and Cyprus back to Germany, and all them things were really pleasant."* (William,
49 resident with dementia, Scheme 4)
50
51

52 Having your own home offered opportunity to maintain some privacy and independent living:
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"I love it. I've got my own flat, and I sit in the lounge, and I go to yoga [...] I like to do my own thing" (Bryony, resident with dementia, Scheme 4)

"You have your own place here and you can choose to mix [with] people if you want, or if you don't want to go to these [activities] in the afternoon, you can go out and do your own time" (Richard, resident with dementia, Scheme 7)

For some, the private flat represented a 'safe haven' away from others:

"When I hear [the other residents being rude] I don't like it at all. I [can] just walk out and come up here and think, 'oh well let them get on with it'" (Annette, resident with dementia, Scheme 2)

"I don't think I want to mix with them out there. [But] in here. Everything is easy." (Thomas, resident with dementia, Scheme 5)

The space also offered private visits with family in contrast to more traditional residential care:

"My auntie has had to go into a care home she's got a bedroom and that's it. There's nowhere to sit. (Family carer 2, Scheme 5)

"[My daughter]'s able to come quite often with the children. So the family is all connected." (Laura, resident with dementia, Scheme 2)

A safe and secure location

A second benefit noted by both residents and their family members was the safety and security that living in ECH provided. Knowing that staff were onsite reassured both residents and family members:

"You've always got somebody you can call. They don't mind if you call [...] But if you pull that, [...] in about a couple of minutes they're coming in and seeing what's the matter." (Peter, resident with dementia, Scheme 5)

"There's always staff on the unit, so if there's a problem, there's staff close by" (Family carer 1, Scheme 5)

ECH also provided a sense of protection from the outside world:

"You hear so many funny stories out there, and then I'm here and I think I'm so fortunate that I'm not out there. So, yeah I feel safe." (Sheila, resident with dementia, Scheme 1)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"Just out in a normal housing street, you've got the issues of people, if they do leave home or they leave the front door open or they answer the door to the wrong person, so those kinds of issues you wouldn't have here so I guess that gives you peace of mind" (Family carer 2, Scheme 5)

For some residents, the safety and security of the location was also related to future planning and the belief that the accommodation could continue to meet their needs as their symptoms developed:

"We didn't want to have to rely on family, who are always there for us, but I just felt I could manage here. If [my husband] got worse, I could manage, if my back went, which it has done since we've been here, we could manage" (Betty, resident spouse, Scheme 3)

But my daughters did notice when I was in the house that occasionally I forgot the odd name or whatever. As I think most people do. So that was a bit of an incentive to come to a place like this as well. [...] Should anything happen, there's help available here. (Richard, resident with dementia, Scheme 7)

Flexible support to sustain a level of independence

A key feature of the ECH concept is the flexibility of care and support available. Resident participants in this study had diverse care and support needs. Some had no planned care and support, whilst others had multiple calls per day to support with activities of daily living. Some residents described staff support as a collaborative effort that supported independence:

"[Staff] come in. Sometimes they get me breakfast. But nine times out of ten I say, no it's all right I can do it" (Frank, resident with dementia, Scheme 8)

'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.' (Nicholas, resident with dementia, Scheme 8)

Other residents required and valued a higher level of support, knowing that staff were on hand to support with eating and drinking. This gave residents peace of mind.

"I haven't got to worry about a thing. [...] Food, meals. It's comfortable." (Rose, resident with dementia, Scheme 5) Having additional staff available in communal areas for ad hoc support was important in supporting residents with dementia:

"I'm not afraid to...I go up and say, 'oh I don't like to be a nuisance but where's the toilet?' If there's no girls about, what can you do? And [staff member] says, 'oh just straight down there, the door on the left'. I say, 'on the left?' He says 'yes', and he showed me, takes me to where it is, but obviously don't take me in. (Katharine, resident with dementia, Scheme 2)

1
2
3 *"They just say, are you coming? Or, [do] you know what's on or something like that".*
4 (Molly, resident with dementia, Scheme 7)

5
6 *'The room downstairs, there's always somebody there to see to anybody or do things*
7 *(Annette, resident with dementia, Scheme 2)*

8
9
10 The quality of the relationships between staff and residents was recognised by both residents
11 and family members:

12
13
14 *"Very reassuring that that you can always go to staff. They're always listening to you,*
15 *which is important, isn't it? They will listen to you and see what your problem is and then*
16 *sort it out really"* (Molly, resident with dementia, Scheme 7)

17
18
19 *"All I can say is, how does mum look when we come in to see her? She looks great. The*
20 *staff have lots of banter with her. She, sort of, warms to that and has a laugh"* (Family
21 carer 2, Scheme 5)

22
23 The flexible staff approach has additional value in enabling people to remain in their own
24 homes during periods of acute illness or during rehabilitation.

25 26 27 28 **Age-friendly convenient living**

29 Many residents commented on the practical design and age-friendly nature of living in ECH.
30 Residents appreciated the practical size of their flat:

31
32 *"It's not too much to clean, you know what I mean?"* (Katharine, resident with dementia,
33 Scheme 2)

34
35 *"I think it's a nice size, everything's a nice size. So you feel quite relaxed here and it's nice*
36 *to come...it's like coming home."* (Donald, resident with dementia, Scheme 8)

37
38 For those residents who managed their own finances, they recognised that having a single
39 inclusive rent and utility bill was a helpful convenience:

40
41 *"It's always warm. Of course, we pay for the heating through the rent, but we don't pay*
42 *separately. Which is an advantage."* (Richard, resident with dementia, Scheme 7))

43
44 *"It's all inclusive, you don't pay for electric. And your water is all-inclusive. [...] once you've*
45 *moved in, and you've got what you need to pay, you know then what's left is yours."*
46 (Delia, resident spouse, Scheme 3)

47
48 In addition, residents noted the convenience that ECH could offer with respect to upkeep and
49 maintenance:

50
51 *"[I] enjoy the garden when it's a nice day. And at least I don't have the problem of*
52 *digging..."* (Richard, resident with dementia, Scheme 7)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"I do some [cleaning] myself. The bathrooms are done by someone because I found them quite awkward to clean" (Colleen, resident with dementia, Scheme 6)

For one resident, the ease of reselling the property after death was also a beneficial convenience despite any loss in value:

"One of the good things here is yes, your property is going to...the value will stay. Well, in fact, the value decreases a certain amount. However you know that your lease, if something happened to both of us, can just be passed back to [Organisation 3]. Your family haven't got to sell it, go through all the trauma of selling, so all of that to me are considerations which you need to make" (Betty, resident spouse, Scheme 3)

Such issues have little featured in research to date and future studies might consider how such arrangements impact upon the decisions to relocate to ECH or other forms of specialist housing.

Social interaction

Within the ECH schemes, activities, mealtimes, and shared facilities offered residents opportunities for social interaction without needing transport or needing to leave the scheme.

Having communal space meant that informal social opportunity was available if you wished:

"I just go on my own and I sit and read a book or do my crosswords. And then by that time other people have come. Then you get chatting" (Sheila, resident with dementia, Scheme 1)

"[We] go down to the restaurant when it's time for tea or you could be sitting in the lounge where it's carpeted just chatting with your friends, with the people you've met while you're in here" (Jane, resident with dementia, Scheme 6)

Schemes 1, 2, 4, 6, 7 and 8 had a café/restaurant, and these could provide a focal point for regular coming together. Although Schemes 3 and 5 did not have a café/restaurant, residents often chose to eat their food in the communal lounge spaces so as to be with other people:

"12 o'clock, dinner time, I take [my meal] over, put it on the side, and whoever's working that day, they'll put it in the microwave and we all have our dinner down there [...] Every day you see [other residents] dinnertime, so of course you just, one or two I speak to" (Rose, resident with dementia, Scheme 5)

In addition to informal social opportunity, schemes also hosted planned activities onsite. For example, yoga, film nights, art groups, bingo, or themed activities. For some people, planned activities were a helpful facilitator for social interaction:

1
2
3 *"The only time that we meet is at the coffee mornings. Or at the curling, whoever attends"*

4
5 (Richard, resident with dementia, Scheme 7)

6
7
8 Some people required prompting or assistance to attend the activity (e.g. due to memory loss,
9 mobility), but there was no need to leave the scheme or arrange transport. Some residents still
10 attended activity outside of the scheme and, for those that were able to, this was an important
11 aspect of freedom, independence and choice.

12 13 14 15 **Opportunity to continue to live as a couple**

16
17 A final advantage noted by some residents was the opportunity that ECH provided to support
18 people to continue to live as a couple. This included residents where one or both parties were
19 living with dementia. Living within ECH supported couples to continue to care for each other
20 with the additional back-up support of staff if required:

21
22
23 *Well I'm the one who has a carer, obviously. She comes in around seven o'clock. Nearly*
24
25
26
27
28
29
30
31 *always a different one, but she gives me a shower, dresses me and would do a lot more*
32
33
34
35 *if I needed it, like getting me breakfast and whatnot. But of course with Robin [my*
36
37
38
39 *husband] here, I don't need it. (Harriet, resident spouse, Scheme 1)*

40
41
42 *The social services moved us into here because [my wife] couldn't cope. If anything*
43
44
45
46
47 *happened to her, I'd just pull the cord and one of the carers or two of the carers came*
48
49
50
51 *and they'd help me. (Barry, resident spouse, Scheme 2)*

52
53
54 Although living together could be done outside of ECH, some residents recognised that this
55 would not be the case in other forms of institutional care:

56
57
58 *"It keeps people out of going into nursing home and things like that, where you would*
59
60 *be separated if one of you was ill"* (Marie, resident without dementia, Scheme 3)

61 62 63 **Challenges**

64
65 In addition to the benefits, residents recognised some challenges inherent within ECH,
66 including the availability of staff, the potential for loneliness, and living with or alongside
67 advancing symptoms of dementia.

68 69 70 **Availability of staff and the reality of "flexible" resourcing**

71
72 Residents and family members recognised that there was often a high turnover of staff and a
73 lack of consistency in care provision:

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"I think that if she gets to know them, but they've had quite a bit of turnover" (Family carer 1, Scheme 1)

"Before, Harriet [my wife] would get a carer for, say, four days in a row. Now you're lucky if you get two days in a row, before you get somebody else" (Robin, resident with dementia, Scheme 1)

Some residents also described support as being rigid:

"In and out [...] I appreciate it's a job to them, not for me" (Laura, resident with dementia, Scheme 2)

"They come in in the morning, help you get washed and dressed and whatever. Then you never see them till lunchtime and so that's...they come in to me about 1 o'clock. Then you don't see them again till about five. Then you don't see them till 10 o'clock at night [...] I do worry about going down, because you could be down there for hours" (Anne, resident with dementia, Scheme 5)

Residents and family members noted that at times, there were insufficient numbers of staff available on demand, there by undermining the value of having staff onsite:

"There's a bit of lack of staff downstairs, so if I didn't have the key fob to get in quite often I wouldn't be able to get in" (Family carer 2, Scheme 1)

I'm mean I'm just sad [Activity Coordinator]'s not here Monday to Friday because I think in all of these places, they need something going on. (Family carer 1, Scheme 4)

Planned support calls could not always be delivered at the preferred time, undermining the sense of control and agency that residents experienced over their care:

It was known that we would go down half an hour before lunch. So when she was handicapped and had to have a wheelchair, the position was officially made half past eleven. But every now and again, with this new system, a girl will appear and Harriet will say 'I'm sorry, you're too early'. 'Oh, quarter past eleven.' You know, it's official. They're doing what they were told. (Robin, resident with dementia, Scheme 1)

As symptoms advanced, some residents required more proactive support from staff if they were unable or unwilling to ask for more support:

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

"I think the problem as well is she doesn't like to bother anyone. She doesn't see it's their job" (Family carer 2, Scheme 1)

Scheme 3 was criticised by residents for relying too heavily on support from other residents or untrained volunteers in place of paid staff:

"They rely too heavily on volunteers who... haven't had the training that staff have"
(Andrew, resident with dementia, Scheme 3)

"I think it is a valuable place for people to live, with dementia, but I know, there is very much a reliance on other residents to do the care, to look out for people, like walking people back to their apartments, it's not staff that does that" (Gill, resident without dementia, Scheme 3)

Loneliness

Despite the reported benefits and promise of social activity that ECH could provide, many residents reported feeling lonely:

"I get lonely" (Anne, resident with dementia, Scheme 5)

"I think my mum, she had a bit of a to do last night, because sometimes she doesn't like being on her own. And, I think weekends, there's not so many people about" (Family carer 1, Scheme 1)

For residents living with dementia, symptoms such as apathy, disorientation, memory loss, poor mobility, or reduced confidence could prevent them from leaving their flat without support or prompting. Although privacy was seen as a benefit, it could also be isolating:

I would say it's friendly, but you've got to join in. You need to go down and have a coffee, or...it's no use just sitting in your room. Because people won't come up to your room. Nobody interferes with you. (Delia, resident spouse, Scheme 3)

The ones on this floor, I see occasionally. But once they're in their flats, I don't see a lot of them. We don't really socialise at all. (Richard, resident with dementia, Scheme 7)

Advancing symptoms of dementia

Residents recognised that ECH could not always support a resident living with more advanced dementia. For example, participants reported former residents who had been moved out of the scheme following aggressive behaviour which had become difficult for residents to live alongside, causing them to feel unsafe, or to lock doors.

Although some couples were living together in ECH and saw the support available as beneficial, ECH could not support all people living with dementia. One resident recognised that the level of care provided would have been insufficient for their partner:

"I think if people, if they've got somebody with them, they can probably live here longer, but I think there comes a point where they won't be able to and they will need that specialist care in a care home, and [my husband] was already there" (Rachel, resident without dementia, Scheme 3)

For Rachel, the level of additional support that she would have had to provide would have been too difficult and compromised her own psychological and emotional wellbeing.

Some residents living with milder symptoms also found living alongside those with more advanced symptoms challenging:

"Most of the people who live here, most of them are all ga-ga anyway, unfortunately brains. They've got dementia and stuff like that, and I just back off from that. Because I know that's the way I'm going to be later on and it's not nice" (Peter, resident with dementia, Scheme 5)

Residents with more advanced dementia could dominate staff time, thereby preventing access to staff support for others. They could also unintentionally interrupt the lives of other residents:

I was watching television and I saw something. And there was this old lady, standing there in a short nightie. This was half past six in the morning. So Harriet got up, knew her and showed her...put her to home. (Robin, resident with dementia, Scheme 1)

"You've got no privacy here. There are people walking and out. Well, staff mostly. I've got [another resident] over the way and she dodders in. Goes to get in the bed." (Peter, resident with dementia, Scheme 5)

1
2
3 Residents without dementia expressed concerns over the level of care available to residents
4 with dementia:
5
6

7 *"If a family put somebody in here with dementia they're going to need a lot more care*
8 *than can be given because it isn't cheap. It's about £18 an hour for care. They're in the*
9 *wrong place. There's quite a few that have been taken to nursing homes"* (Marie,
10 resident without dementia, Scheme 3)
11
12
13
14

15 Concerns generally related to stereotypes of more advanced dementia, echoing stigmatised
16 views of what it means to live with dementia (Alzheimer's Society, 2019):
17
18

19 *There's a stigma. And people...I haven't felt it too much personally, but if I was more*
20 *advanced, I don't know.* (Andrew, resident with dementia, Scheme 3)
21
22
23

24 **Discussion**

25 Having a sense of ownership over your home, familiar possessions, and the option of a private
26 life (with or without family) away from the broader activity in the scheme underpinned ECH as
27 a location for independent living, rather than institutional care. Findings suggest that this is a
28 significant benefit understood by residents and their families that can support a sense of
29 control, agency, normalcy, and identity (Anonymous, Vallely et al, 2006; Burns et al, 2009;
30 Barrett, Atkinson & Evans, 2016) and can be conceptualised in Series' (2022) view of the 'home
31 as haven' offering a place of safety and a retreat from the world. However, the benefits of
32 having a private space to which a person can retreat has to be balanced against opportunities
33 for social engagement, which may become diminished as symptoms of dementia progress.
34 Specialist staff dedicated to supporting people with dementia who can prompt or remind
35 residents to attend activities can mitigate against the risk of potential isolation, but their
36 availability will depend upon how the scheme has been resourced. Where care is provided
37 flexibly, there is potential for the changing needs of people living with dementia to be readily
38 met but rigidity of care can result in extended periods of time where a resident may be isolated
39 in their apartment.
40
41
42
43
44
45
46
47
48
49
50
51
52

53 Safety and security have been noted to be a key motivator for moving into ECH (Barrett, 2020)
54 and data demonstrates that this is seen as a significant benefit, both by residents and families.
55 Evidence suggests this dimension has a two-fold aspect; firstly, the presence of staff supports
56 residents to feel safe. Technology built into the scheme enables them to alert staff should an
57
58
59
60

1
2
3 incident arise giving residents confidence that their needs can readily be met in an emergency.
4 This is important for those with and without care packages. The flexibility of support available
5 enables independence to be maintained as fully and for as long as possible with care being
6 scaled accordingly as required. Secondly, the building itself provides a layer of safety from the
7 outside world. Residents can choose to whom they open the door to their apartment with an
8 added layer of protection through progressive privacy via fobbed access and a centralised
9 front entrance. The open-door policy of ECH, however, affords freedom to residents to come
10 and go as they choose. As symptoms of dementia progress, this can prove challenging for
11 families and staff in balancing the risk versus safety of residents. This is an aspect of ECH which
12 requires further research into the applicability and usefulness of the Deprivation of Liberty
13 Safeguards (Anonymous).
14
15
16
17
18
19
20
21
22
23

24 The benefit of living in an environment with an age-friendly design and ethos was valued by
25 residents who felt the burden of household chores, gardening and finances was alleviated thus
26 enabling them to enjoy their apartment and grounds without the responsibility of
27 maintenance. Moving to new accommodation prior to dementia symptoms progressing can
28 aid with familiarisation of new spaces and help residents with dementia to orientate to their
29 new environment.
30
31
32
33
34

35 ECH almost uniquely offers the opportunity to remain living as a couple if residents choose to
36 do so. People living with dementia expressed the value they placed on this citing the support
37 they got from their partner as being balanced with the care which could be provided from
38 within the scheme. However, it is important to note that the spouse without dementia may
39 find their care commitments limit the value on offer from the scheme for themselves.
40
41
42
43
44

45 Social inclusion lies at the heart of ECH provision offering the opportunity for shared dining,
46 entertainment, activities and interaction with others both within the scheme and the wider
47 community. The important point noted here by residents was the extent to which this
48 supported their own autonomy in choosing whether or not be involved and at what level. For
49 some this was the ability to remain connected to the outside community, for others it was
50 simply to sit in a shared environment whilst others enjoyed the communal activities and dining
51 opportunities. As noted above, where a person's symptoms of dementia progress, support
52 may be required for them to continue to be involved in the social aspects of life within the
53
54
55
56
57
58
59
60

1
2
3 scheme. This will be dependent upon the flexibility of staffing available and how the scheme
4 is resourced which in some cases may limit opportunities.
5
6
7
8
9

10 **Conclusions**

11 Findings from this study highlight valuable benefits of living in ECH for residents with
12 dementia, including a sense of ownership, safety, security, social connectedness, and flexible
13 staff support. ECH fosters a strong sense of identity, stability, and agency through ownership
14 of their homes and familiar possessions. The flexible support system allows residents to
15 maintain independence while receiving necessary assistance. However, challenges for
16 residents with dementia include staff availability, loneliness, and managing advancing
17 symptoms. Insufficient staff resources can lead to limited engagement and support. Loneliness
18 may arise from reduced social interaction despite communal spaces. As dementia progresses,
19 ECH may struggle to provide adequate support, potentially leading to transfer to specialized
20 care facilities. Data from other participants (staff, social care professionals) reveal further
21 challenges (Anonymous). While ECH offers benefits, addressing these hurdles is essential for
22 effective dementia care. Improving staff training, promoting person-centred care, and
23 fostering an inclusive community are critical for enhancing residents' well-being and quality
24 of life in ECH.
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40

41 **Limitations**

42 This paper explored the lived experiences of residents and family members, providing new
43 insight into the advantages and disadvantages of ECH for people living with dementia. Some
44 limitations, however, should be noted. Firstly, despite efforts to create an inclusive, diverse
45 sample drawn from rural, urban and city locations, the participants were all White British.
46 Darton et al (2022) similarly note that limited ethnic diversity in ECH is common potentially
47 identifying an under researched area. Secondly, the participants involved were identified by
48 gatekeepers, usually the scheme manager. This may present some bias in the selection of
49 residents who were not only those with capacity and thus more able but may have resulted in
50 schemes choosing participants who held more positive views of living in ECH.
51
52
53
54
55
56
57
58
59
60

References:

ADASS (2022) Putting people at the heart of new housing development. *Housing Learning and Improvement Network*. Available at:

<https://www.housinglin.org.uk/assets/Resources/Housing/OtherOrganisation/Putting-people-at-the-heart-of-new-housing-development-Coproducing-the-place-we-call-home.pdf>

Alzheimer's Society (2019) *Hidden no more: Dementia and disability* Available at <https://www.alzheimers.org.uk/about-us/policy-and-influencing/2019-appg-report> Accessed 23rd August 2023

Atkinson, T.J., Evans, S., Darton, R., Cameron, A., Porteus, J. and Smith, R., (2014). Creating the asset base—a review of literature and policy on housing with care. *Housing, Care and Support*, 17(1), pp. 16-25. doi: 10.1108/HCS-09-2013-0017.

Barrett, J. (2012) Provision for people with dementia within Housing with Care: Case studies from HDRC Steering Group Providers HDRC https://housingdementiaresearch.files.wordpress.com/2012/07/report-on-provision-for-people-with-dementia_v1-6_jun2012.pdf

Barrett, J., Evans, S. and Pritchard-Wilkes, V. (2020) 'Understanding and supporting safe walking with purpose among people living with dementia in extra care, retirement and domestic housing', *Housing, Care and Support*, 23(2), pp. 37-48. doi: 10.1108/HCS-03-2020-0004.

Barrett J (2023) Provisions for people living with dementia in housing with care settings in England. *Housing, Care and Support* 26(2), 29-40. <https://doi.org/10.1108/HCS-01-2022-0005>

Brooker, D. J., Argyle, E., Scally, A. J. & Clancy, D. (2011) 'The Enriched Opportunities Programme for people with dementia: A cluster-randomised controlled trial in 10 extra care

housing schemes', *Ageing and Mental Health*, 15(8), pp. 1008-1017. Doi: 10.1080/13607863.2011.583628.

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., Macfarlane, A., Maclean, M., Patel, M., Runnicles, D., Oshinaike, T. and Smith, C. (2009) *Older People's Vision for LongTerm Care*. York: Joseph Rowntree Foundation

Crowther, N. (2022) *Place, People, Purpose & Power: Promoting the wellbeing of people living with dementia through personalised care and support*. Dementia Change Action Network

Darton, R. and Callaghan, L. (2009) 'The role of extra care housing in supporting people with dementia: Early findings from the PSSRU evaluation of extra care housing', *Journal of Care Services Management*, 3(3), pp. 284-294. Doi: 10.1179/csm.2009.3.3.284.

Darton, R. A. (2022) Extra Care Housing: The Current State of Research and Prospects for the Future, *Social Policy and Society*. Cambridge University Press, 21(2), pp. 292–303. doi: 10.1017/S1474746421000683.

Dutton, R. (2010) 'People with dementia living in extra care housing: Learning from the evidence' *Working with Older People*, 14(1), pp. 8-11. doi: 10.5042/wwop.2010.0071.

Evans S., Vallely S., Croucher K. (2014) The role of specialist housing in supporting older people with dementia. In: Downs M., Bowers B. (eds) *Excellence in dementia care research into practice*, Milton Keynes, UK: Open University Press, pp. 331–342

Evans, S. C. *et al.*, (2017) 'A community hub approach to older people's housing', *Quality in Ageing and Older Adults*, 18(1), pp. 20-32. doi: 10.1108/QAOA-02-2015-0008.

Evans, S., Atkinson, T., Cameron, A. *et al.* (2020) 'Can extra care housing support the changing needs of older people living with dementia?' *Dementia*, 19(5), pp. 1492-1508. Doi: 10.1177/1471301218801743.

Feng, I.-M., Chen, J.-H., Zhu, B.-W. & Xiong, L. (2018) Assessment of and improvement strategies for the housing of healthy elderly: Improving quality of life. *Sustainability*, 10, 722.

Garin, N., Olaya, B., Miret, M., Ayuso-Mateos, J.L., Power, M., Bucciarelli, P. & Haro, J.M. (2014) Built environment and elderly population health: A comprehensive literature review. *Clin. Pract. Epidemiol. Ment. Health* 10, 103–115.

Government Office for Science. (2016) *The Future of Housing and the Built Environment in An Ageing Population*; Government Office for Science: London, UK.

Grimmer, K., Kay, D. Foot, J & Pastakia, K. (2015) Consumer views about aging-in-place. *Clinical Interventions in Aging* 10, p.1803

Holland, C., Carter, M., Cooke, R., Leask, G., Powell, R., Shaw, R., West, K., Clarkesmith, D., Collins, J., Hagger, B., Kay, A., Lambie, J., Liddell, L., Wallis, S., & Boukouvalas, A. (2015). *A longitudinal evaluation of the ExtraCare approach*. Collaborative research between the Aston Research Centre for Healthy Ageing and the Extra Care Charitable Trust

1
2
3 Hadjri, K., Rooney, C. & Faith, V. (2015) Housing choices and care home design for people
4 with dementia. *Health Environments Research and Design*, 8(3), p.80-95

5
6 Iwarsson, S., Wahl, H.W., Nygren, C., Oswald, F., Sixsmith, A., Sixsmith, J., Széman, Z. &
7 Tomson, S. (2007) Importance of the home environment for healthy aging: Conceptual and
8 Methodological background of the European ENABLE-AGE Project. *Gerontologist* 47, p. 78-
9 84

10
11
12 Kitwood T (1997) *Dementia reconsidered: The person comes first*. Open University Press:
13 Maidenhead.

14
15
16 Kneale, D. & Smith, L. (2013) Extra Care Housing in the UK: Can it be a Home for Life? *Journal*
17 *of Housing For the Elderly*, 27(3), p.276-298

18
19 Marmot, M. (2020) Health equity in England: The Marmot Review 10 years on. Available at:
20 <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>.

21
22
23 Mawhorter, S.I., Wilkie, R.Z. & Ailshire, J.A. (2023) Inequality in housing transitions during
24 cognitive decline. *PLoS ONE*, 18(4) <https://doi.org/10.1371/journal.pone.0282329>

25
26 Oatley, R. & Atkinson, T. (2023) Viewpoint 107: Supporting people living with dementia in
27 extra care housing. *Housing Learning & Improvement Network*. Available at:
28 [https://www.housinglin.org.uk/News/New-Housing-LIN-Viewpoint-No-107-presents-
29 valuable-insights-from-The-DemECH-project/](https://www.housinglin.org.uk/News/New-Housing-LIN-Viewpoint-No-107-presents-valuable-insights-from-The-DemECH-project/)

30
31
32 O'Malley, L. and Croucher, K. (2005) 'Housing and dementia care: A scoping review of
33 literature' *Health and Social Care in the Community*, 13(6), pp. 570-577. Doi: 10.1111/j.1365-
34 2524.2005.00588.x.

35
36
37 Pettersson, C., Malmqvist, I., Gromark, S. & Wijk, H (2020) Enablers and Barriers in the
38 physical environment of care for older people in ordinary housing: a scoping review. *Ageing*
39 *and Environment*, 34, p. 332-350

40
41 Rapaport P, Burton A, Leverton M, Herat-Gunaratne R, Beresford-Dent J, Lord K, Downs, M.,
42 Boex, S., Horsley, R., Giebel, C. & Cooper, C.. (2020) "I just keep thinking that I don't want to
43 rely on people." a qualitative study of how people living with dementia achieve and maintain
44 independence at home: stakeholder perspectives. *BMC Geriatric* 3;20(1):5

45
46
47 Riseborough, M., Fletcher, P., & Gillie, D. (2015). Extra care housing what is it? Housing LIN
48 factsheet
49 [1.https://www.housinglin.org.uk/assets/Resources/Housing/Housing_advice/Extra_Care_Hou
50 sing_What_is_it.pdf](https://www.housinglin.org.uk/assets/Resources/Housing/Housing_advice/Extra_Care_Housing_What_is_it.pdf)

51
52
53 Series, L. (2022) *Deprivation of Liberty in the Shadows of the Institution*. Bristol University
54 Press

55
56 Sixsmith, A. & Sixsmith, J. (2008) Ageing in Place in the United Kingdom. *Ageing*
57 *International*. 32, p.219-235

1
2
3 Smith, M., Brown, M., Ritchie, L., Papadopoulou, C., & Tolson, D. (2022). Living with dementia
4 in supported housing: A systematic review and thematic synthesis of qualitative
5 research. *Health & Social Care in the Community*, 30(3), e589-e604. Doi: 10.1111/hsc.13618.

6
7
8 Stewart, J., Crockett, R., Gritton, J., Stubbs, B. & Pascoe, A. (2014) Ageing at home? Meeting
9 housing, health and social needs. *Journal of Integrated Care*, 22, p. 242–252.

10
11 Twyford, K. (2016) *Individuals with dementia living in extra care housing: An initial exploration*
12 *of the practicalities and possibilities*. Housing Learning and Improvement Network: London

13
14
15 Twyford, K. (2018) *People with dementia living in Extra Care Housing: An exploration of the*
16 *practicalities and possibilities*. PhD Thesis. University of Sheffield

17
18 UK Government (2023) 'Government unveils taskforce chair to boost older people's housing'
19 Available at: [https://www.gov.uk/government/news/government-unveils-taskforce-chair-to-](https://www.gov.uk/government/news/government-unveils-taskforce-chair-to-boost-older-peoples-housing)
20 [boost-older-peoples-housing](https://www.gov.uk/government/news/government-unveils-taskforce-chair-to-boost-older-peoples-housing) [Accessed 03.08.23]

21
22
23 Volkmer, A., Bruns, C., Zimmerer, V., Varley, R., & Beeke, S. (2023). Giving Voice to People
24 With Dementia and Their Carers: The Impact of Communication Difficulties on Everyday
25 Conversations. *International Journal of Qualitative Methods*, 22

26
27 World Health Organisation (2018) WHO Housing and Health Guidelines. Available at: [WHO](#)
28 [Housing and health guidelines](#)

29
30 Yin, G., Lin, S. & Chen, L. (2023) Risk factors associated with home care safety for older
31 people with dementia: family caregivers' perspectives. *BMC Geriatric* 23, 224

32
33
34 **[2 anonymous articles have been removed to protect author identification]**
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1 Participants by type and gender

	Resident with dementia	Resident spouse without dementia	Non-resident family member	Resident without dementia	Scheme staff	External adult social care professionals
Total number	34	6	5	9	34	12
Male	11	2	3	2	1	5
Female	23	4	2	7	33	7

Table 2 Summary of case study sites

Scheme ID	Model	Location		No of Apartments	Facilities
1	Integrated	Central England	Town	40	Communal lounge, dining, laundry, shop, hobby room, garden
2	Specialist	Central England	Town	42	Communal lounge, dining, laundry, hairdresser, garden
3	Specialist	S.E England	Metropolitan	49	Communal lounge, laundry, garden
4	Integrated	Central England	Metropolitan	260	Large hall, dining, gym, hairdresser, shop, hobby room
5	Specialist	Central England	City	33	Communal lounge, garden
6	Separated	N.E. England	Rural	40	Communal lounge, dining
7	Separated	N.E. England	City	50 Integrated 20 Separated	Communal lounge, dining, laundry, hairdresser, hobby room, garden
8	Integrated	Central England	Large Village	54	Communal lounge, dining, laundry, hairdresser, hobby room, garden