Together in later life: how extra care housing can support couples affected by dementia

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Abstract

Purpose – *The purpose of this paper is to present insights into how extra care housing (ECH) can support couples, where at least one partner is living with dementia. ECH is a model of housing with flexible care and support that supports older people to live independently. Couples are enabled to continue to live together in a self-contained flat or apartment with additional support for either or both parties as required.*

Design/methodology/approach – *This paper reports on findings from a large study of living with dementia in ECH (DemECH) that involved qualitative interviews with ECH residents affected by dementia, ECH staff and adult social care professionals were conducted across eight ECH schemes in England.*

Findings – *Data offer insight into how ECH can support couples might navigate their relationship, maintain a sense of togetherness and adapt to the challenges posed by changing care and support needs and cognitive decline.*

Research limitations/implications – *The findings of this study are based on a small sample with limited diversity, which is not claimed to be representative. Participants were identified by gatekeepers at each research site, which may have presented some selection bias.*

Originality/value – *This paper provides novel insights into the living experiences of couples residing in ECH where at least one partner is living with dementia. Couples' experiences in ECH have been little considered in research thus far.*

Keywords *Dementia, Alzheimer's disease, Extra care housing, Housing with care, Supported living, Couples, Couplehood, Unpaid care, Living*

Paper type *Research paper*

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Introduction

Dementia affects over 57 million people worldwide (World Health Organization, 2025). In the UK, the number of people living with dementia is projected to reach 1.4 million by 2040 (Alzheimer's Research, 2023). As a progressive neurological condition, people living with dementia often require increasing levels of daily care and support. Unpaid carers, often spouses or long-term partners, provide most care outside institutional settings (Livingston *et al.*, 2017; Henderson *et al.*, 2019). A Dementia Carers Count (2024) UK survey found that 47% of carers are spouses or partners.

While unpaid caregiving is widely associated with emotional and physical strain (Livingston *et al.*, 2017), positive aspects are also reported, such as feelings of purpose and pride (Quinn *et al.*, 2022). Most people over 65 in the UK live with a partner, a growing trend because of an ageing population, narrowing life expectancy gaps and increasing new later-life relationships [Office for National Statistics (ONS), 2023]. Given that dementia is predominantly diagnosed in older adults and chronic health conditions become more common with age (Maresova *et al.*, 2019), it is not uncommon for both parties in a "couple" to have one or more chronic conditions. This adds complexity to both the relationship and the caregiving dynamic of mutual support.

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Qualitative research reports that couples affected by dementia strive to maintain togetherness despite shifting roles (Wadham *et al.*, 2016; Clark *et al.*, 2019; Dunn *et al.*, 2024). Intimate relationships can anchor both parties (with and without dementia), providing emotional continuity, mutual recognition and reinforcing identity (Moyle *et al.*, 2011), as well as reciprocal practical support that might negate the need for services. As dementia progresses, the relationship is renegotiated, shifting towards caregiving and dependency. While some couples adapt, others can experience loss, communication challenges and emotional distance (Conway *et al.*, 2020; Sinclair *et al.*, 2018), redefining their shared identity. Dementia occurs in the context of relationships that shape a person's sense of self and identity (Brooker, 2007; Tieu and Matthews, 2024). Thus, considering couples as a unit, as well as individuals, can enhance both parties' well-being in the context of life with dementia.

Extra care housing and dementia

Access to appropriate housing is essential for dementia care and a fundamental right for people living with dementia (Twyford and Porteus, 2021). Most people in the UK living with dementia reside in their own homes, but for some, specialist supported accommodation is crucial. Extra care housing (ECH) has evolved as a specialist option for older people in the UK and internationally and aligns with an established policy principle that promotes sustaining independent living (Older People's Housing Taskforce, 2024). A range of terminology is used in across the globe for comparable models (e.g. assisted living and housing with care) and no unified definitions exist (Atkinson *et al.*, 2014). The proportion of older people living in UK ECH has been reported to be lower than those in USA and Australia (Jones Lang LaSalle, 2015). Although there are no contemporary figures on residents, as of 2025, there are approximately 1,940 ECH schemes in the UK, including 1,729 schemes in England, which contribute to an estimated 520,000 retirement housing units across England (Elderly Accommodation Council, 2025; Twyford and Porteus, 2021). Provision is diverse in size, location and design, with specialist, separated and integrated models available for people with dementia (see Oatley and Atkinson, 2024).

The principles underpinning ECH promote safe and supported independent living (Smith *et al.*, 2022), offering private, self-contained apartments within a larger scheme, with communal facilities (e.g. restaurant and hairdresser) and 24-h flexible care (Oatley and Atkinson, 2024). Unlike traditional residential care, ECH provides various tenures, including ownership, rental and lease agreements, while care services are funded separately to the housing provision. ECH supports "aging in place", by adapting care to changing needs, making it theoretically well-suited to dementia's progression. However, it is now widely accepted that it cannot guarantee a "home for life" and certain symptoms of dementia (e.g. aggression, walking with purpose, self-neglect and night-time care needs) can mean ECH is no longer suitable for a person with dementia (Barrett, 2020; Barrett *et al.*, 2016; Evans *et al.*, 2020; Atkinson *et al.*, 2023). That said, approximately one-fifth of ECH residents are estimated to live with dementia, including those without or unwilling to seek diagnosis (Barrett, 2020). While providers offer flexible, needs-based support, rather than diagnosis-led care, research on good practice for dementia in ECH remains limited.

A key advantage of ECH over care homes is that couples can move in together with onsite care as needed (Oatley and Atkinson, 2024). No data exist on the number of couples living in ECH or how are affected by dementia (i.e. where one or both partners have dementia). Canadian research on assisted living (similar to ECH) found that couples affected by dementia move in out of marital responsibility rather than synchronicity of care needs, suggesting value in flexible housing with care options. However, UK research on prospective residents reported that couples valued staying together longer and reducing caregiver stress, but worried about losing community connections and uncertainty over when to relocate, suggesting choice to relocate for couples are complex (Poyner *et al.*,

2017). Although evidence is limited, these issues appear relevant beyond Canada and the UK, with couples elsewhere facing similar challenges in balancing relationship needs, care and social connections.

This paper presents findings on couples from a broader study on dementia and ECH (DemECH; Atkinson and Oatley, 2022). DemECH identified benefits of ECH for people with dementia included homeownership, a safe, age-friendly location, flexible support, onsite social interaction and the opportunity to live as a couple while receiving individualised care (Oatley and Atkinson, 2024). This paper explores couples' experiences of living in ECH, offering insights into how ECH can support couples and highlighting critical knowledge gaps.

Methodology

This DemECH project addressed the following question:

Q1. What are the advantages and disadvantages of different models of extra care housing for people living with dementia and those that support them?

This paper reports on project findings related specifically to the theme of living experiences of couples affected by dementia in ECH. Ethical approval was granted by the Health Research Authority (21/HRA/3769). A project advisory group consisting of professionals with expertise in housing, social care and dementia and ECH residents living with dementia supported research development, design and implementation.

Eight ECH schemes were purposively identified via the advisory group, NIHR ENRICH network and desktop research to represent different providers, locations, sizes and model of provision (Table 1). Face-to-face semi-structured interviews were conducted with 34 residents living with dementia, 6 resident spouses without dementia, 5 non-resident family

Table 1 Summary of extra care housing schemes

Scheme	*Location*	*Size*	*Facilities*	*Model*
Scheme 1	Market town (population 45k) Central England	40 apartments	Shared lounge, restaurant, laundry, shop, hobby room and garden	Integrated (people living with dementia live in and among other residents)
Scheme 2	Town (population 90k) Central England	42 apartments	Shared lounge, restaurant, laundry, hairdresser and garden	Specialist (exclusively for people living with dementia)
Scheme 3	Metropolitan borough (population 200k) South East England	49 apartments	Shared lounge, laundry and garden	Specialist
Scheme 4	Metropolitan city (population 1.1m) Central England	260 apartments	Village hall, restaurant, gym, hairdresser, shop and hobby room	Integrated
Scheme 5	City (population 350k) Central England	33 apartments	Shared lounge and garden	Specialist
Scheme 6	Market town (population 5k) Northeast England	40 apartments	Shared lounge and restaurant	(Former) separated (exclusive area for people living with dementia separated from the larger integrated scheme)
Scheme 7	City (population 800k) Northeast England	70 apartments (50 integrated and 20 separated)	Shared lounge, restaurant, laundry, hairdresser, hobby room and garden	Separated
Scheme 8	Large village (population 14k) Central England	54 apartments	Shared lounge, restaurant, laundry, hairdresser, hobby room and garden	Integrated

Source(s): Authors' own work

members, 9 residents without dementia and 34 scheme staff. In all, 12 external adult social care professionals (e.g. social workers and commissioners) were also interviewed using Microsoft Teams. Interviews were recorded, transcribed and pseudonymised. Residents were given the choice about whether to participate alone or with another person. Seven residents with dementia chose dyadic interviews (either with a resident spouse or family carer). This approach was adopted for ethical reasons to ensure participants felt comfortable, retained control over their mode of participation and were well supported to communicate their experiences. Joint interviews carry potential limitations, such as one dominating the conversation or a reluctance to disclose sensitive information in front of the other. However, in practice, these dynamics were not readily apparent in the data.

Participants living with dementia were identified by staff based on their knowledge of diagnosis and observed symptoms. While this may have introduced selection bias, staff hold privileged knowledge of residents, making them well-placed to identify individuals able to provide rich insights. Despite efforts to recruit a diverse sample, all residents were White British and those in relationships were in heteronormative partnerships, reflecting limited diversity in the UK ECH population (Darton, 2022).

Under the *Mental Capacity Act 2005,* participants living with dementia were deemed able to consent to participate unless demonstrated otherwise. An information sheet was discussed to assess understanding, retention, weighing of information and communication of decisions. A process model of consent (Dewing, 2007) ensured researchers were alert to any indication a participant wanted to withdraw. All participants were able to provide written informed consent, although a consultee process had been approved if needed, likely reflecting staff selection bias excluding those with capacity concerns. Participation was confidential, except for disclosures posing serious harm, of which none occurred.

A template analysis approach (Brooks *et al*., 2015; King, 2012), reported on elsewhere (Oatley and Atkinson, 2024), guided the examination of data in response to the research question. The coding template was developed iteratively, combining deductive codes informed by existing literature (e.g. ageing in place; Atkinson *et al*., 2023) with inductive codes arising directly from the data (e.g. carer stress). Data generation, coding and analysis were conducted concurrently, allowing insights from early transcripts to shape ongoing coding. Both authors independently coded transcripts and met regularly to discuss and refine the template. Additionally, the advisory group reviewed the relevance and clarity of the developing template. Data were analysed across and within participant types at both semantic and latent levels. A template excerpt is included in Supplementary Material 1. Findings concerning the perspectives of people living with dementia (Oatley and Atkinson, 2024) and model variation (Oatley and Atkinson, 2024) have been reported elsewhere.

Findings

Data demonstrated that ECH could support couples where one or both partners have dementia, allowing them to live together as care needs evolved. While this project focussed on the broader experience of individuals with dementia in ECH, the sample included seven heteronormative couples (six where one partner had dementia, one with both) who directly experienced life in ECH. For transparency, interview mode (solo or dyad) is indicated in Table 2, enabling readers to consider how the data generation circumstances may have shaped accounts. Data from other residents, care staff or social care professionals are included where relevant to couple experiences.

Among these couples, care and support varied in type and allocation for the partner with or without dementia. Some had no care package, where others had daily care and support for either or both partners. Quantitative data on care hours were not collected.

Table 2 Detail of participant couples affected by dementia and interview context

Scheme	*Couple participants (pseudonymised)*	*Partner living with dementia*	*Interview context*	*Additional notes*	*Demographic information*
1	Harriet and Robin	Robin	Together	–	White British, heteronormative couple
2	Maureen and Barry	Maureen	Barry interviewed alone	Maureen no longer living in ECH	White British, heteronormative couple
3	Delia and Ron	Ron	Delia interviewed alone	Ron did not participate in project	White British, heteronormative couple
3	Betty and Andrew	Andrew	Together	–	White British, heteronormative couple
3	Rachel and Simon	Simon	Rachel interviewed alone	Simon not living in ECH	White British, heteronormative couple
4	Ava and William	Ava and William	Together	–	White British, heteronormative couple
7	Maggie and George	Maggie	Together	–	White British, heteronormative couple

Source(s): Authors' own work

Couplehood

Staying together was an important concern, irrespective of the health of each partner:

> [ECH] keeps people out of going into nursing homes and things like that, where you would be separated if one of you was ill. (Amanda, resident without dementia, Scheme 3).

For some couples, moving to ECH fulfilled a shared ambition to continue living independently together, offering emotional and psychological benefits in planning their future:

> However life changed, we were going to be capable of independent living and that was very important to both of us (Betty, resident spouse, Scheme 3).

For Betty, ECH's safety and security supported her fluctuating health, providing a stable environment she believed slowed her husband's symptoms, reflecting a shared well-being:

> I'm happy here and in a physical situation that I can cope with quite well now […] that keeps everything on an even keel, that obviously helps Andrew[husband], so therefore he can stay perhaps at a level without it getting any worse for that much longer. (Betty, resident spouse, Scheme 3).

Staff also believed that staying together could have emotional and psychological significance for couples and saw it as a key benefit of ECH:

> To be separated from someone, which again would happen in a nursing home or residential care, you're separated and you're no longer sleeping with the partner that you've slept with every night, and you don't get up in the morning and have that cup of tea with them and all the rest of it. (Staff 3, Scheme 2).

Couples frequently spoke in terms of "we", reinforcing togetherness in past experiences, present life and future planning:

> Ava: We were brought up like that, you have to clean, I buy stuff to keep it clean, you know?
>
> William: Yeah.

(Ava and William, both living with dementia, Scheme 4).

> We manage everything ourselves, so far anyway. (Maggie, resident spouse living with dementia, Scheme 7).

There was evidence that togetherness mattered beyond co-residence in ECH. Rachel lived in Scheme 3, but not with her husband (living with dementia), whose needs the scheme

could not meet, yet couplehood had still structured her daily routine, including regular visits to her husband's care home while he was alive:

> I used to go three days a week over to his care home and it took me two and a half hours each way and I spent seven hours there. (Rachel, resident without dementia, Scheme 3).

In a second example, staff described a woman living with dementia in the scheme, while her husband remained in their previous home. The privacy of the ECH apartment offered the couple space to "do" daily life together:

> James would come and visit Moira every single day, and he'd spend quite a lot of time here with her, they'd sit on the settee holding hands watching the television, they would cook a meal together, they'd wash the pots. [. . .] So, he had his life here with [his wife], but also his life at home, so he had got that space for himself. (Staff 3, Scheme 6).

This demonstrates that while ECH can help couples maintain shared life, some benefit from individual space, finding alternate ways to retain their couplehood, indicating the structure and motivation "togetherness" can provide in later life.

Mutual support

A key benefit of ECH for couples was providing a location in which they could provide mutual care and support, with back-up staff support if required. This often applied to couples where only one partner had dementia, though it was not always this person who required support:

> I'm the one who has a carer, obviously. She comes in around seven o'clock. Nearly always a different one, but she gives me a shower, dresses me and would do a lot more if I needed it, like getting me breakfast and whatnot. But of course, with Robin [husband] here, I don't need it. (Harriet, resident spouse, Scheme 1).

Robin was living with dementia, but still provided care to his wife, reducing the need for staff input, providing flexibility to their daily routine and providing a sense of continuity and commitment in their relationship.

Some couples where both were living with dementia could also be enabled to continue mutual support, particularly where strengths were complementary:

> He was still very mobile while the wife was less mobile, so he would do things like carrying and moving, passing her things, but her memory at that point was a lot better than his. And they really worked off each other. (Staff 1, Scheme 8).

Staff noted that couples' mutual support was strengthened by the familiarity and trust they had in each other:

> We used to assist him with his medication. That was a thing he was quite anxious about because he could never remember how many tablets he should be taking and what for, whereas the wife always remembered, 'you have seven tablets', and she'd go, 'yeah, that's your seven, that's fine for you to take'. It gave him that reassurance because that was coming from his wife. (Staff 1, Scheme 8).

Having staff onsite to provide additional care and support when needed could provide immediate practical and emotional reassurance that supported people in their care roles:

> If anything happened to her, I'd just pull the cord and one of the carers or two of the carers came and they'd help me. (Barry, resident spouse, Scheme 2).

> When I need any help at all, like when [my husband] falls over, just pull the cord and they come up and get him up for me and yeah, then they'll ring then for two, three days to see whether he's fine. (Delia, resident spouse, Scheme 3).

Onsite staff could reduce the impact of acute incidents (e.g. falls) helping couples more readily manage fluctuating care needs. For Delia, staff and assistive technology (door alarm) were crucial in ensuring her husband's safety and supporting her caregiving role:

> I've got a sensor on the door. Because he will some nights get up and wander. So, they fitted me a sensor. Then if he opens the door, it goes off. Then it rings downstairs. And then [. . .] but I'm used to it. By the time that's gone off, I've caught him. (Delia, resident spouse, Scheme 3).

Professionals recognised that their back-up support was key to sustaining the unpaid care partner as dementia advanced:

> Because they're struggling on their own to support their loved one and having the support network that [we] can provide takes some of that pressure off of them as well. (Local authority staff 1, Scheme 1).

Delaying or preventing a move to residential/nursing care

Data indicated that for a person living with more advanced dementia, informal care and support from an onsite partner could delay or prevent a relocation to residential or nursing care. Partners often provided essential supervision and support:

> He couldn't [live here without my support], no. He couldn't, no. (Delia, resident spouse, Scheme 3).

ECH staff also recognised the role of partner care in sustaining residence:

> There's definitely got to be that caveat that if somebody's living here and their partner, [. . .] independently that person on their own, actually when you look at their skills, would not cope with living here on their own. (Staff 1, Scheme 3).

> We do have a couple upstairs that the gentleman cares for [. . .] well they do have care providers but he's [. . .] if anything happens during that time, he mainly deals with anything. (Staff 1, Scheme 4).

For couples where both partners were living with dementia, it was suggested separation accelerated symptom development, and thus, co-residence could sustain ageing in place:

> Staff 1: They were here for six years in total, before they both moved on at different times to a care home.
>
> Staff 2: One who went to the care home and then we [. . .].
>
> Staff 1: And then the wife followed, didn't she, afterwards. Because after her husband went to the care home her dementia really progressed very quickly.

(Staff 1 and 2, Scheme 8).

Despite co-residence benefits, one partner's escalating care needs could force couples to separate:

> Christopher had to go into a home, because he was getting nasty with his wife and everything and she couldn't cope anymore. (Staff 1, Scheme 1).

Such transitions could be distressing for the partner remaining in ECH:

> I go to [neighbouring resident] every single day, ever since they took him away, because she was in quite a state when they took him. She's got over that. She's getting over it, but she's lonely. (Harriet, resident spouse, Scheme 1).

If the partner without dementia died first, then it could create a sudden, complex crisis for the surviving partner, especially if they had relied heavily on them for care:

> The difficulties we've then had, when we've had to look at this not being the best place for them, is perhaps when a spouse has died, and the person with dementia has been left. Depending where they are on that journey, you know, we can't really cope. (Staff 2, Scheme 3).

While schemes may be supportive of a person with dementia when the care partner is still there, this does not necessarily last long when that person dies:

> That person [living with dementia] is settled here, this is what they know, this is what they're familiar with. But then, the whole village will not want to [support] for very long, and, some people won't want to do it at all, so then it gets to be difficult. I think then it's not helpful to the person with dementia, because they're starting to get bad vibes. (Staff 2, Scheme 3).

Carer need for support

Data also highlighted that living together could mean that the partner providing more care was not always able to get the maximum benefit from living in ECH:

> I don't join in anything because I've got Peter all the while. But I probably would join in one or two of the different classes if I had the chance. (Delia, resident spouse, Scheme 3).

Rachel reflected upon how it might have been for her had her husband moved into ECH:

> [It] would have made me feel like I'd always got to be with him, so I'd have gone back to the situation when I was living in my house and it was like he was my shadow, I couldn't do anything. (Rachel, resident, Scheme 3).

This suggests that Rachel saw her husband's presence as a threat to her independence. Meanwhile, Delia, despite recognising it was becoming increasingly hard, remained committed to her caregiving role and saw opportunities for respite as important to this:

> I'll go down and have a coffee with [two girls]. Which is a break for me. (Delia, resident spouse, Scheme 3).

Scheme 3 hosted a regular support group for any unpaid resident carers. This was much valued, demonstrating the benefit of recognising and providing proactive support to unpaid carers regardless of where they live:

> I can regularly go to a carers' group, with a small group of people who understand, without me having to say very much, nodding heads straightaway, to just unburden sometimes. You know, it's not all the time, but that's what helps me so much. (Betty, resident spouse, Scheme 3).

Within ECH's shared living context, benefit arise from not only organised support but also readily-accessible informal peer support. However, living alongside peers also carried the risk that one's caregiving might be judged:

> Another time I happened to go down late, and she was fussing all over him again. [. . .] I turned to her, I said "I've told you before, leave him. He can do what he likes". Went back to my table, looked over my shoulder, there she was, putting his salt and pepper on. Oh. [rolls eyes] (Robin, living with dementia, Scheme 1).

Discussion

These findings explore couples' experiences in ECH where one or both have dementia, highlighting how they navigate relationships, maintain togetherness and adapt to changing care needs. Rather than providing a generalisable account, this study highlights an underreported aspect of dementia care in this setting. Further interrogation is warranted to inform policy, practice and the housing with care options.

A key benefit of ECH is its ability to offer couples a shared life within a safe and secure environment, with optional additional care (Oatley and Atkinson, 2024). ECH allows couples

to "age in place" together, adapting to evolving care needs, while preserving intimacy. Support within couples is often reciprocal, with complementary strengths fostering stability and reinforcing shared identity. This stability is linked to enhanced well-being and a perceived slowing of dementia progression. However, ECH cannot always maximise well-being for both partners, reflecting wider findings on the limitations of ECH as a "home for life" for people with dementia (Barrett, 2020; Barrett *et al.*, 2016; Evans *et al.*, 2020; Atkinson *et al.*, 2023), while also highlighting the challenges of caring for resident partners.

"Couplehood", defined as shared identity and togetherness, is central to helping couples manage the challenges of dementia (Hellstrøm *et al.*, 2005; Conway *et al.*, 2020). Couples often approach dementia as a joint challenge, striving to sustain existing roles (Gallagher and Beard, 2020). This study suggests that contributing to each other's care, supplemented by professionals, reinforces marital responsibility and purpose. Reciprocity strengthens resilience (Conway *et al.*, 2020), underpinning the importance of preserving togetherness (Wadham *et al.*, 2016; Clark *et al.*, 2019; Dunn *et al.*, 2024) even as roles evolve. For those unable to live together in ECH, maintaining a couplehood dynamic remains central to well-being. Structured visits and shared private spaces help sustain relationships, underscoring the importance of flexible support that acknowledges relational aspects of dementia care (Brooker, 2007; Tieu and Matthews, 2024). These insights have relevance beyond ECH, across care settings.

Ownership of a private living space and opportunities for personal homelife, such as family visits or flat customisation, are valued by people with dementia (Oatley and Atkinson, 2024; Barrett *et al.*, 2016). Living alongside one's partner reinforces this sense of home, providing emotional familiarity, intimacy and practical care and support. Familiarity and trust between partners can aid daily care routines, including medication management. ECH staff recognise that this dynamic provides reassurance and stability for the partner with dementia. Emergency support systems (e.g. staff and assistive technology) ensures that caregiving partners have immediate assistance if needed, thereby reducing caregiver stress and burnout risk.

Couples also use shared decision-making and future planning to manage anticipated transitions (Sinclair *et al.*, 2018; Kemp, 2008). Moving to ECH is sometimes a joint decision to sustain the relationship while preparing for future care needs. The diversity of care needs within ECH (Oatley and Atkinson, 2024; Atkinson *et al.*, 2023) makes it ideal for couples with evolving support needs, as there are always likely to be peers to provide empathetic support. Peer support can help carers feel they are coping (Smith *et al.*, 2018), though the public nature of shared living can subject one to judgement and stigma. Shared spaces (e.g. restaurants) provide a stage on which one's caregiving might be judged, presenting an additional complexity to the dynamics of inclusion. Indeed, stigma related to dementia in ECH is well established (Barrett *et al.*, 2016; Evans *et al.*, 2020; Atkinson *et al.*, 2023), yet judgment of unpaid care provision remains underexplored.

Despite these benefits, advancing dementia can necessitate separation. Symptoms, such as aggression, walking with purpose, self-neglect and high night-time care needs, may prevent continued ECH residency with dementia (Barrett, 2020; Barrett *et al.*, 2016; Evans *et al.*, 2020; Atkinson *et al.*, 2023). As symptoms progress, relationship imbalances can threaten the shared "we" identity couples strive to sustain (Hydén and Nilsson, 2015; Dunn *et al.*, 2024), undermining "couplehood" and leading to feelings of lost independence and identity (Dunn *et al.*, 2024). Some care partners in this study described increasing care responsibilities diminishing their autonomy. These findings highlight the need for dyadic interventions that proactively support couples through disease progression and transitions within ECH.

Separation because of death or relocation can be distressing, thus, requires careful support. Onsite peers may be beneficial in supporting the grieving process and reducing the risk of social isolation (Smith *et al.*, 2018), but it is important to note that the surviving partner is not always the one without dementia. More research into good practice in this

scenario is required as where partners are in place to provide care and supervision, staff seem more willing to support a resident with advancing dementia. Once that partner is gone, how staff and other residents respond and interpret the behaviour of the person living with dementia (who may be experiencing acute grief) must be explored.

Conclusions

This study highlights the experience of couples living together in ECH. A central implication is that ECH's ability to support couples to remain together despite asynchronous care needs is a key appeal. This includes supporting couples where one or both parties are living with dementia to age in place, making it a valuable option in dementia care. Such findings highlight the need for policy to ensure housing is integrated into national dementia care strategies and to explicitly recognise couples as "units" of care. Staying together allows couples to maintain their caregiving roles, uphold marital responsibility and sense of couplehood. The reassurance provided by having staff onsite can help couples continue to provide mutual support, but commissioners must also ensure that funding, provision and eligibility criteria are designed to sustain this. As dementia progresses, changes to the relationship can undermine the benefits ECH offers, placing stress on the caregiving partner. ECH cannot guarantee couples will remain together if care needs exceed the support capacity, and nursing or residential care may still be required. For providers, this underlines the importance of equipping staff with the skills to assess and support relational aspects of dementia, in addition to individual care needs, as well as adopt flexible care planning that adapts to evolving needs and includes contingency plans and protocols for separation or bereavement and proactive support for care partners (e.g. peer support programmes, respite opportunities and specialist counselling).

While previous ECH research has focused on individuals, the relational nature of dementia underscores the need to explore couple dynamics. Given housing's crucial role in care, further exploration of options for couples affected by dementia is needed, particularly considering an ageing population more likely to be living together (ONS, 2023) and rising UK dementia rates. The growing trend of late-life relationships brings further complexity to this issue (ONS, 2023). Developing adaptable care plans in partnership with couples, carer support initiatives, transition-planning and peer support opportunities may be important dimensions of ECH provision that enable couples to thrive together. Future research should examine different couple formations, diverse ethnicities and sexualities and track well-being across time.

Limitations

This paper does not claim to have fully explored couple experiences but highlights an underexamined topic with implications for research and practice. The limited sample diversity reflects UK ECH populations (Darton, 2022) and gatekeeper selection bias may have favoured those with positive ECH experiences.

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Ethical statement (information removed from anonymous main document)

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Further reading

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Supplementary material

The supplementary material for this article can be found online.

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