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Stimulating Thinking on dementia policy and practice from the
Dementia Services Development Centre at the University of Stirling

02. Housing at the Crossroads

This is the right moment to treat dementia as a long-term condition and to use all available evidence to help people manage dementia as *their* condition. This paper explores how this one change in approach could provide a more settled and less emotional approach to the future development of services for people with dementia – one which has positive implications for the “housing offer”. If dementia is at a particular crossroads, so is housing, as the immediate and long-term challenges offered by dementia become unavoidable. So what are the responses available for meeting these needs? What can be done which is both practical and most effective?

Our understanding of what it means to live with dementia has improved in recent years. Choices about how and where people with dementia can live effectively are clear. Most say they would prefer to live in their own homes for as long as possible. Such independent living is now more possible than ever thanks to changing behaviours, home adaptations and more of the right kind of support. A higher quality of life is increasingly within reach of people with dementia at home. This sounds like a positive picture and it largely is. The wider context was explored in the first Iris “Thinking Long Term”.

However the way dementia is portrayed and framed in society is a persistent problem. The prevailing images of dementia frame a less positive picture. Dementia seems firmly embedded in the thinking of many as an unrelenting blight on individuals, families and neighbours. People with dementia are still too often portrayed as people who disturb the quiet enjoyment of others, who disrupt families and upset established ways of living.

Challenging and re-framing the way people with dementia are portrayed is now a pressing priority. So is equipping people, the public and professionals, with the right level of understanding of dementia and the appropriate knowledge to deal with difficult situations.

There is a significant amount of activity at a policy level about the way forward for dementia. Some of it does provide a framework for action. But is this at the expense of real engagement with what will make a lasting difference? Are some fundamental issues being missed in the pursuit of head-line grabbing initiatives? How much of what is happening really passes the test of applying what is actually known to work, based on evidence?

Dementia: Housing at the Crossroads, a year-long programme designed to support debate and discussion around the ways in which housing and housing related services can play a full role in service redesign and improving the lives of people living with dementia. It draws on a round-table discussion held at the Royal Society of Medicine on the 12 March 2014 involving leading figures from older peoples’ housing organisations, general needs housing providers and health organisations.

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A more constructive and accurate way of looking at dementia would be to emphasise its shared characteristics with other long-term conditions and mental health. This provides a more stable framework for long-term policy and immediate improvement in the lives of people with dementia, wherever they live.

The Housing Offer

What is clear, based on sound evidence, is that housing and housing-related support services have a key role to play in helping people with dementia to achieve their aspirations.

Traditionally the housing offer has largely consisted of designated housing for older people. This where in some cases the sound evidence about how housing can be made “dementia-friendly” has been put to good use - by addressing issues such as lighting, acoustics, physical design and outdoor spaces. But there is much more that housing can do.

- *specialist housing* can ensure that someone’s home is care ready
- *housing-related support services* can not only help people to stay in their own homes for longer but also play a vital role in making communities dementia friendly
- but most critically of all *everyone involved in housing* can increase levels of diagnosis and support which help people live independently

So far it would not be unfair to say the approach to addressing the challenges of housing has been in some ways tentative, inconsistent and short-term. Equally the Housing Offer around dementia has largely developed in ways that are reactive and fragmented.

By approaching dementia positively as a long-term condition it becomes clear how each element of the Housing Offer can play a key role and how everyone involved in housing can make a practical contribution.

Meeting the Dementia Challenge

Housing and housing-related services can rise to the challenge. But to do so effectively these 8 things need to happen:

1 Pathways

Housing organisations themselves need to redefine their contribution to the care pathway for frail older people (including people with dementia) better. In part it depends on developing greater clarity about what the contribution is at different stages of pathway and how the housing offer connects to others.

So local examples are important not just to illustrate what this looks like, but also to promote the type of exemplary practice which will convince other partners in the pathway.

One example could be where housing and housing-related support organisations work with existing providers to promote both independent living and models of support that demonstrably help people stay in their own homes for as long as possible.

Housing organisations can advocate for outcomes-based commissioning approaches. These can focus on the opportunities for secondary prevention and the development of models that genuinely help people to stay out of institutional forms of provision and – if an acute admission is necessary – help them to return home.



Housing-related support services help people to stay in their own homes for longer and play a vital role in making communities dementia friendly.

2 Staff Knowledge

Some housing staff are unaware of the steps they can take to help people with dementia and their carers. Some of the common behaviours of people with dementia make some residents unwilling to live side by side with them. However, these can in most cases be easily dealt with by knowledgeable and experienced staff.

Staff are also critical in making secondary prevention interventions such as encouraging early diagnosis, promoting exercise and stimulation, making specific environmental adaptations and community support.

Housing organisations should not rely on simply training staff to have the knowledge and confidence they need to do this effectively on their own. There is a real case for taking a wider strategic approach for collectively managing behaviours. There is less value in a member of staff applying this knowledge on their own if others are not guided by the same principles.

3 Care Co-ordination

Good quality care co-ordination is pivotal to finding effective ways of wrapping care around individuals and ensuring the right levels of secondary prevention are in place. This is certainly what primary care is looking for. Traditionally responsibility for care co-ordination has sat in the acute sector. However, there are increasing levels of interest in passing this role to the third sector. This offers opportunities and risks for housing organisations.

Arguably the most exciting result for housing associations and for people with dementia would be for housing associations to pilot models of (super) care coordination. This is not a huge step to take as many housing associations are at the heart of local neighbourhoods and already connected to the local. The risks lie more in not grasping opportunities like this which are emerging from changes in the way public services are being commissioned and delivered.

4 Organisational Standards

Housing associations can commit themselves to a genuinely holistic approach to dementia. This is more than (just) being “dementia-friendly”. It involves ensuring that the whole organisation is doing the right thing for people with dementia and their carers. Organisations should already be ensuring that their housing is well-designed and that staff are well trained. This is becoming expected as standard by clients, commissioners and relatives.

Many do this but audit results suggest there is a lot of variation. An exemplary organization will make sure it is looking honestly at the whole picture for both quality and commercial reasons.

At one level exemplary might mean differentiating between dementia awareness training for staff who have relatively short interactions with people with dementia from more in-depth training for those who may be managing more complex situations.

At another level it might mean ensuring that staff who have partners or close relatives with dementia can discuss their caring responsibilities with their line manager or HR department.



5 Transfer of Care

Redesign of pathways is not easy. It potentially involves multiple organisations and individuals. Each is likely to need assurance that any change will work. One critical issue is what will achieve the safe transfer of care. This revolves around the development of a shared understanding of risk and of necessary, practical management arrangements which mitigate the risks, in way that provides assurance.

In large part this will come down to developing a shared understanding of quality and risk. Housing professionals need to assure themselves, and others, that they have the skills to manage without referring. Health professionals will be looking to develop their levels of confidence in the services being provided. They will want to be assured that there will be no increase in safeguarding alerts and evidence that they are operating successfully and safely within the neighbourhood where they live.

Protocols which spell out different forms of intervention to meet different behaviours can help develop shared understanding and confidence as well as being of huge practical benefit to staff whatever their role in the pathway.

6 Floating Support

The continuation of floating support has come into question but, thought about creatively, it could provide a key part of the housing offer. Floating support has suffered from a lack of accurate specification and is under threat as Supporting People is phased out. Clinical Commissioning Groups (CCGs) want to see more community-based models of care and secondary prevention.

However Housing Associations could develop floating support services that address a specific need – to complement secondary prevention and successful hospital discharge. It is likely CCGs will see the added value of such measurable, marketable and saleable models of floating support.

7 Communities

Housing organisations can play an important leadership role in developing (dementia) friendly communities. Although there is a lot of activity around dementia-friendly communities there is still a lot of uncertainty about what is meant, with prevalence for “top-down” approaches driven by government initiatives. However a truly dementia-friendly community is likely to be one where there is awareness of dementia and an understanding of how to respond, built from the “bottom-up” using exist local assets or growing new ones.

There are already good examples of how housing organisations have developed housing schemes for people with serious mental health problems, working with local residents to create support in local communities. This model can easily translate into the world of “dementia-friendly”. Such an approach is more likely to promote better understanding of dementia at a community level and provide the basis for an asset-based community development approach which will work over time.

This plays to the value of housing organisations acting on what they know works, connecting to sound evidence and practical experience from across the sector - especially around what practitioners, carers and people with dementia themselves know works.

The current focus on dementia-friendly communities might seem positive but there is a danger that this simply generates pressure to do something quickly, with evidence being set aside. So the role of housing organisations in advocating for an evidence-based approach could be of lasting value in helping more people live independently and also making sure immediate momentum is in fact sustainable progress.



Such an approach is more likely to promote better understanding of dementia at a community level.

8 Health and Wellbeing

Housing associations have long been committed to investing in initiatives to strengthen communities and to aid individuals. The Public Services (Social Value) Act 2012 requires those commissioning or procuring public services contracts to consider how the work can improve the wellbeing of the area.

Initiatives such as Wellbeing Evaluation assist with social impact measurement and will help to develop the understanding of what housing associations can achieve at a neighbourhood level. There is a strong case here for diverting investment towards community models of provision given the savings that can be made from preventing admission to institutional forms of care. More local evidence of what those savings would look like would help unlock the door and housing organisations may need to take a more confident lead in making those calculations.

Conclusion

Housing is at the crossroads. But there are a number of clear and positive routes forward for the housing offer. The key decision for housing organisations, individually and collectively, now is what action to take. The opportunities are there. Confidence and knowledge are still issues which need to be addressed head-on. Time is pressing. It would be a shame if housing failed to fulfil its potential to play a pivotal role in determining a positive future for people with dementia in the UK. There is no need for that to be the case.

Roundtable Conclusion

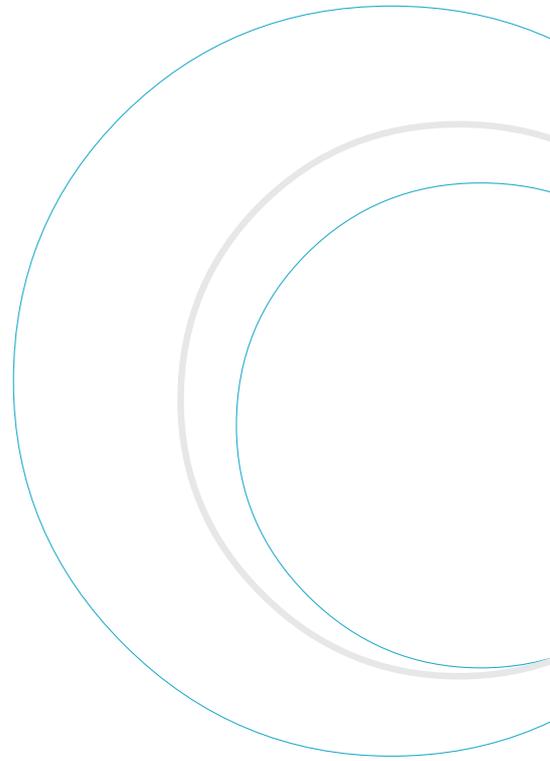
We believe that housing services are essential to the successful transition of dementia from palliative specialism to long term condition.

We know that simple changes to the home environment are an essential part of someone being able to live independently for longer and avoid institutional forms of provision.

We are concerned that we are still playing 'catch up' if evidence is going to be embedded in housing services – even specialist services.

Housing Associations, because of their strong neighbourhood presence make them ideal coordinators of secondary care and the facilitators of dementia friendly communities that are genuinely "bottom-up".

A distinction needs to be made between the evidence that is needed to make changes to the way housing works and the evidence that is required to redirect investment.



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Yvonne Arrowsmith	Family Mosaic
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The Dementia Services Development Centre (DSDC) exists to improve services for people with dementia and their carers throughout the UK and beyond. We do this through research and teaching and by supporting workers and organisations that provide care for people with dementia. Our staff of academics, health and social care professionals, researchers and event organisers provide comprehensive dementia education and training, consultancy and research services. The Centre's flagship Iris Murdoch Building is a model for dementia friendly design. This open and welcoming environment provides inspiration for our team's work in designing and remodelling care homes for people with dementia. Research into understanding the needs of people and how to support them is central to our work. The Research Group are members of the University of Stirling who conduct research into our understanding of dementia and related matters. Their research projects help to improve the quality of life and services for people with dementia and their carers.



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