The views expressed in this interview are based on my own knowledge and experience and do not necessarily reflect those of the Housing LIN

INTERVIEW FOR 2017 DEMENTIA AWARENESS WEEK WITH SUE GARWOOD, HOUSING LIN DEMENTIA LEAD

1) As the Housing LIN dementia lead, what are you aiming to achieve?

- Improving knowledge and skills through a wide variety of means – website, newsletters, resources and knowledge exchange events
- Recognition of the important role the sector can play in enabling people with dementia to live as well as possible. To this end...
    - Improving dementia awareness, understanding and practice within the housing sector
    - Raising awareness and understanding of Housing's contribution amongst health and social care professionals in order to achieve inclusion

2) When you talk about housing, what do you mean?

- Physical environment and what people call home
- A large and diverse workforce
- A wide range of services provided by housing organisations apart from accommodation per se

3) When does it become inappropriate for a person with dementia to carry on living in a housing setting?

One could argue that the idea of "appropriate" in this question only has relevance because of the legal distinction between domiciliary care and residential care for registration purposes.

In practical terms, considering whether it is "appropriate" for the person to carry on living there, we need to think what we mean by "appropriate". Can the person's needs be met there? What would they like to do? Would it be in their best interests to stay or move elsewhere? And this has to be balanced with the landlord's duty of care to other residents. Not easy and no definitive answer.

Essentially boils down to two dynamic and interactive things: the unique characteristics of the particular individual and the features of the particular housing setting and local context. So what do I mean?

1. The nature of the behaviours or needs triggering concern
2. Level of risk to individual and others and whether these can be reduced to acceptable levels
3. Level of disruption to other occupants and whether this can be contained e.g. through use of technology

These in turn will depend on

1. The setting – is this sheltered/retirement housing or extra care? One would expect people with dementia to be able to be supported in ECH for longer than in standard sheltered schemes, simply because of staffing levels and possibly better building design, although even in ECH wide range of variations
2. On-site staffing levels and roles
3. Expertise and skills of housing and care staff involved to understand what underlies the behaviour and come up with imaginative solutions that address the underlying need, so supporting the individual and other residents
4. The culture and attitudes of other occupants and how susceptible these are to changing
5. Availability of peripatetic and specialist services
6. The physical layout and location of the site
7. Availability of relevant technology
8. Availability of informal support network

Some of these are fixed. Some can be altered.

So, while it is wise to develop move-on criteria and not PROMISE a home for life, how they apply must be assessed individually. An assessment is needed – probably multi-disciplinary – which takes into account all of these factors to work out what is best for the person.

Mental Capacity Act principles must apply:

1. Assume capacity
2. Support individual to make own decision
3. Must be allowed to make unwise decision so long as they have capacity – and it does not adversely affect other occupants
4. Must be in individual's best interests
5. Least restrictive option

So important to try and understand what has triggered the behaviour. Can the matters of concern be dealt with without a move through:

- trying to address what has triggered the behaviour, and
- exploring options that can contain the situation to the satisfaction and benefit of all concerned?

Does the person have the mental capacity to understand the concerns around their behaviour and make a decision about what to do?

1. If so explore options with them, both for staying where they are with additional input in the form of support, activities, technology etc and/or for moving elsewhere
2. If not: Meet with other relevant people including family carers, relevant housing staff, Adult Social Care etc to make a best interests decision. Law Commission proposal that individual's wishes are given greater weight in March 2017 report on mental capacity and deprivation of liberty.

Two other issues for me:

1. *What do you do if the person lacks the mental capacity to terminate their occupancy agreement and there is no Lasting Power of Attorney (LPA) in place?*

- Legally, at present should be done through the Court of Protection but often this is done through a best interests decision-making process, or not done properly at all.
- There seems to be a big issue around the quality of best interests decision-making which housing providers are experiencing when someone can no longer be supported where they are. The approach adopted by some local authorities is said to be superficial and not involve all the relevant parties.

- Housing provider is left grappling with the issue of how to terminate the occupancy agreement if the person lacks the capacity to agree and there isn't an LPA in place. In addition there are practical problems; if there is no-one to clear the property, the contents may be left there and arrears may accrue.
- It is an area which still needs bottoming out
- I can't see anything in the Law Commission's proposals that will resolve this. There is a recommendation to tighten up procedures under the MCA s5 protection if a public body proposes a long term move, but it strikes me that it doesn't resolve the legal issues or necessarily ensure improved practice, although it should help – if it becomes law.

2. *When is it inappropriate for a person with dementia to move into a housing setting like extra care housing in the first place?*

- There seems to be an unwillingness to grapple with this question. Some local authorities seem to see extra care housing as a complete replacement for residential care and consider themselves entitled to "place" people in ECH.
- Obviously depends on the features of the particular scheme but given that even extra care is about supporting people to live in their own homes independently, someone in the more advanced stages of dementia who needs constant supervision and care may not benefit at that stage from moving to ECH; the person may be more likely to be isolated in their own apartment and not welcomed by other residents.
- It may be better for the person at this stage to move to a residential care setting where care provision should be more flexible and responsive.
- The way care is now commonly commissioned and configured in ECH – care and add-on model using personal budgets – is not conducive to flexibility and responsiveness.
- Also, people more likely to learn their surroundings, build friendships and be accepted into the community if they move in to the scheme at an early stage in their dementia.
- All of that said,
    - Many of the same factors apply as in my earlier answer – It needs to be assessed on an individual basis: is it in P's best interests? Are they likely to be able to abide by the occupancy agreement? And so on.
    - My own feeling – as I outlined back in 2005 in an article for the Journal of Dementia – is that you need a range of different types of provision and a spectrum, because what suits one person may not suit another

4) The feelings of other residents/tenants towards people living in the service with dementia is not always positive – what can housing providers do to help this?

Partly connected to the previous question and no easy answers. And it's not only people with dementia who can get stigmatised of course.
JRF Better Life research – *Promoting supportive relationships in HWC* – Karen Croucher and Mark Bevan

- Promote an ethos of tolerance and support throughout the organisation and support front-line staff to provide leadership in housing schemes
- Staff fundamental to setting tone – need understanding of dementia and other vulnerabilities, strong commitment to values, and the skills to deal with prejudice and discrimination firmly but tactfully.
- Try to nip abusive behaviour in the bud – important not to appear to condone discriminatory behaviour by not challenging it, or indeed rewarding the perpetrators by giving them additional responsibilities – hence power

- Try to prevent cliques from ruling the roost by enabling less vocal occupants to set up/take part in different interest groups and activities, sharing out tasks etc
- Awareness raising amongst residents – needs to be ongoing
- Ensure language, images and communication coming from organisation are clear and welcoming of diversity so people moving in can't say they didn't know what to expect
- Think carefully about when to leave it to residents to sort out own issues and when to intervene
- Play a brokerage role introducing people to one another in the background
- Try to unite people around a specific task or project, and ensure everyone has a voice by various means – e.g. one-to-ones and small group discussions as well as residents' meetings
- Try to ensure care plans include support to enable people who need help to take part in community life e.g. Enriched Opportunities Programme
- Link with wider community to dilute some of the unhealthy groupings
- Partner with external agencies to provide activities and opportunities for residents and people from the wider community
- Have dementia champions – either residents or staff

I do appreciate that there is no quick fix, and that with cuts in revenue left, right and centre, having the staff available to devote time and energy to these things is a real challenge, but it's probably worth it in the long run, both for the residents and the organisation. Example of the Country Close Enquiry.

5) Is this why you think it is so important to raise awareness and understanding of dementia amongst housing staff through training tailored to settings and roles?

- Absolutely - there will be people who have or develop dementia with whom staff come into contact and there'll also be customers who have had discriminatory attitudes for years
- How staff respond can make the difference between people with dementia and their carers living well and independently or not

6) If housing staff have a good understanding of dementia and some of the issues facing people living with it, what sorts of things can they do to help?

- Respond with understanding and empathy
- Recognise that going down an anti-social behaviour route would be inappropriate
- Notice signs and help to get a diagnosis
- Provide information, advice, signposting, support and/or advocacy depending on particular role in areas such as:
    - Furnishing and layout of property
    - Aids, adaptations, repairs and maintenance
    - Housing options
    - Benefit entitlements
    - Access to support services and peer support groups
    - Access to meaningful activities like Abbeyfield's art and nature initiatives
- Prevent problems from escalating and becoming crises, e.g. entering the wrong flat, getting lost, getting into arrears, letting pots boil dry or water overflow
- Design and develop new properties and services that cater specifically for people with dementia, or are general but dementia-friendly e.g. specialist housing or support services

7) What broadly do you think staff need to know about?

- Clearly breadth and depth will depend on particular roles, but things like:
    - Signs and symptoms of dementia
    - Basic information about different types of dementia and the things dementia can be confused with (delirium and depression)
    - Each individual's unique experience & expression of dementia depending not only on the brain damage but also their personality, life experiences, general health, values and culture etc →
    - Person and relationship centred responses that identify assets and aspirations as well as needs
    - Understanding behaviour as communication – And Still the Music Plays
    - Importance of listening to people with dementia and enabling them to exercise choice and control as far as possible, and related to that →
    - Empowering as well as safeguarding aspects of Mental Capacity Act
    - Deprivation of liberty as it relates to the housing sector – needing authorisation from the Court of Protection if someone in a housing setting lacks the capacity to agree and needs to be deprived of their liberty for the purpose of "care and treatment"
    - Dementia design principles including their rationale

8) Why do you always emphasise that dementia training needs to be tailored specifically for the housing workforce?

A) Distinctive elements within the housing sector

- Ability to influence or control the physical environment
- Most staff do not provide hands-on care
- Issues in relation to mental capacity and deprivation of liberty
- Balancing rights and responsibilities of all occupants in a housing scheme

b) Staff need to be able to see the relevance of it to the setting and their particular role – needs to be meaningful.

9) What characterises a dementia-friendly organisation?

- A culture and ethos that is inclusive and dementia-friendly throughout the organisation
- Leadership and support from top to bottom
- Training across the board tailored to specific roles and level of likely contact with people who live with dementia
- Dementia-friendly policies and procedures
- Dementia-friendly employment practices and contracting terms

10) How can housing providers demonstrate and share the work they are doing to become more dementia friendly?

- Join the DAA
- Sign up to commitments in the Dementia-friendly housing charter
- Write a case study for publication and inclusion on the Housing LIN website
- Give presentations at conferences
- Respond to calls for good practice examples and consultations

- Take part in research
- Participate in groups like the DHWG

11) What are some of the things that impede the sector's ability to fulfil our role in enabling people with dementia to live well in their own homes?

Both internal and external factors:

- A tendency for health and social care professionals not to recognise the contribution of the sector at macro (service commissioning) and micro (individual support planning) levels
- Tendency for housing professionals to be treated as in some way inferior
- Housing sector prioritising other things such as funding of supported housing and welfare reform
- Some parts of the housing sector failing to recognise the relevance and how it can actually make good business sense

12) Finally then, do you think that progress is being made by the housing sector and more generally in the country towards becoming dementia-aware and dementia-friendly?

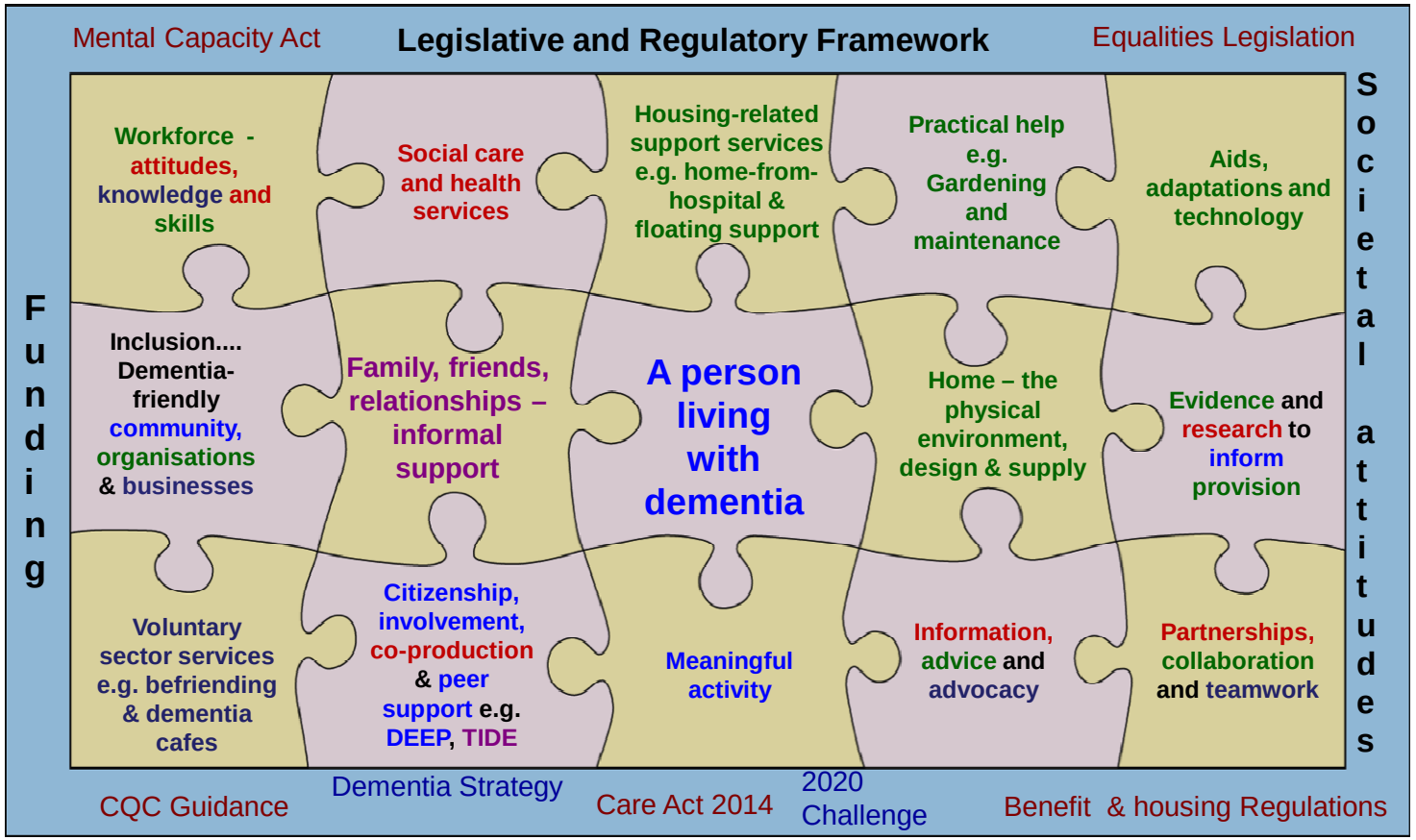
Both in the housing sector and the country at large is growing awareness and understanding and lots of good initiatives, but fragmented and still a long way to go.

I'd just like to share with you my vision of where we need to get to. Whether we are talking about individual housing schemes or local communities, they do not all need to look the same – indeed would be very peculiar and dull if they did. But for people with dementia to live as well as possible, all the different facets need to dovetail and complement one another.

I see it like a jigsaw puzzle where all the pieces fit together to make a complete picture, but the pictures across the country are all different. People may identify different or additional pieces but the jigsaw on the following page gives an idea of what I mean.

Sue Garwood – Housing LIN Dementia Lead

PERSON-CENTRED COMMUNITY SUPPORT



THE DESTINATION – AN INCLUSIVE COMMUNITY