

quality of life
charitable trust

RESEARCH PROGRAMME 2013-14



Helping smaller housing associations
become dementia friendly

Their experience and the impacts on
their policy and practice

A collaborative evaluation from Moyra Riseborough and Adrian Jones

Riseborough Research and Consultancy Associates

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Foreword

Throughout its 25 year history, the Trust has had a clear focus on helping disadvantaged people to enjoy a better life so, when we asked Moyra Riseborough to conduct our first research project in 2010, we wanted it to be of practical help to social housing providers and older person's organisations to improve the lives of the people to whom they provide services.

Moyra's central theme was adopting person-centred working, whereby organisations look at their way they operate, putting the customer first and tailoring their approach to the individual. She showed that this does not need to involve major structural change or great expense, as small differences in the way people behaviour and interact with their customers can have a significant impact.

My role with the Trust is voluntary and my day job is at the Field Lane Foundation, a charity providing care and support with a focus on people with learning difficulties and dementia. Everyone is an individual and we have a person-centred approach to each and every one of them. Not only are we supporting the individual, some of whom have extreme physical problems, but their families as well, so each case is very different.

The trustees decided to look for our second project at the work of smaller housing associations that, by and large, do not have the resources of their larger counterparts, but can know their customers better and make changes more easily and faster. We were encouraged by the enthusiasm and willingness to work with us and we have been following a group as they become dementia friendly in everything they do.

This report tracks their progress and we hope that others will want to learn from their experience.



A handwritten signature in black ink, which appears to read 'David Huckler'. The signature is written in a cursive style and is underlined with a thick black line.

David Huckler

September 2014

Chapter 1: Executive Summary

Chapter 2 gives the background to the report explaining it is based on evaluating the progress of four small housing associations who decided in 2013 to work towards becoming dementia friendly organisations. They are Heantun HA in Wolverhampton, Racing Homes HA in Newmarket, Waltham Forest HA and Innisfree HA in London. Sutton Housing Society in London was meanwhile at the start of a programme of work part funded through a Department of Health initiative. Amongst other things the Society aimed to improve the experiences of older tenants and better support them to age in place in a housing with care scheme. Tenants included people with dementia. The Society shared information about its work with us.

The housing associations had already done a considerable amount of work to improve their services for people with dementia and the chapter describes some of their work. These housing associations were amongst eight associations who participated in Learning Workshop we organised for Orbit Charitable Trust and the decision to follow four associations afterwards came out of that workshop.

The chapter considers what being dementia friendly means and it draws on current thinking about dementia friendly communities to do this. We give a short potted overview of theories about dementia including reasons why the concept of a dementia friendly community is seen as a helpful one. Next the chapter looks at the views of people with dementia and their carers. The gaps and issues that they face are addressed head on by people who sign up to the ideas of supporting dementia friendly communities. Finally the chapter asks if it is possible to establish dementia friendly housing organisations. The rest of the report looks at the experiences of five small housing associations as they went about putting ideas into practice.

Chapter 3 describes detailed experiences of the five small housing associations. It begins by reflecting on their starting points and goes on to examine the methods they used to establish dementia friendly housing organisations. Their progress is considered by comparing the action they took to the factors associated with dementia friendly communities. Factors such as challenging the stigma of dementia; ensuring people with dementia are involved in decisions; training and equipping staff and tenants with facts; including people with dementia better so they can go about their lives, find their way and obtain the support and help they need. Also helping people get the early diagnosis they need.

The key points made in the chapter are:

- The relationships the housing associations made with their local Alzheimer Society and local colleges were vital for bringing in initial dementia awareness training.
- Training made people want to get involved – people *chose* to become Dementia Friends

- After initial dementia awareness training the associations are trying to decide what works best for them in terms of keeping staff up to date and getting involved in additional dementia education.
- The small housing associations have broken new ground – we know much more now about *how* to make changes that are dementia friendly
- We know more about the specific changes that promote a sense of community for people from diverse communities including multi ethnic communities in East London, people from horse racing backgrounds and people from the Irish community
- Some of the minor design and physical changes to housing stock cost very little
- Changes to front offices and ways of operating so they are dementia friendly cost time but not a huge amount of additional resource.
- Other more far reaching physical changes to the fabric of the housing stock, colour and design changes were embedded into long term refurbishment and upgrading/maintenance plans.
- Also through applying for sums of money from Government and other funders e.g. Joseph Rowntree Foundation.
- Some changes are being achieved through working with partners e.g. better support planning and person centred working.
- Small housing associations show very clearly how they can work within their communities of place and attachments in unique ways
- They can achieve a great deal because they know their tenants and service users very well – they can tailor services to meet individuals needs and respond because there is that personal link - it is an advantage over larger housing organisations

We anticipate that there will be additional insights to come from the work being undertaken by Sutton Housing Society including the roles that way finding, having a a sensory room and a garden play in people's well-being. We look forward to finding out more in due course.

Chapter 4 focuses on the reasons why leaders and key staff decided to invest time and energy into becoming dementia friendly housing organisations. The chapter also looks at the reasons why training was so important and at how the organisations started to change their practices, processes and policies.

The key points from the chapter include the following:

Motives for involving the organisation in the year-long exercise were a mix of ethical and social as well as thinking about future business and needs.

1. Sutton Housing Society had slightly different motivations since although the Society had started a programme of work to introduce improvements for older tenants (including people with dementia) before our work began, the Society was also introducing additional changes in its housing with care scheme which was funded by the Department of Health. This was due to a successful bid to the DH by the London Borough of Sutton. We included the Society's activities because they were relevant.
2. Most of the organisations began with their action plans and got support for a whole organisation change from their Boards of management
3. The associations usually started by addressing the easier targets first.
4. Training brought many benefits and was responsible for staff looking afresh at their everyday practice and processes.
5. Small but highly specific changes brought big changes e.g. changing the way support planning was done so that the person with dementia is at the centre.
6. Changing reception areas and display areas so they include materials about supporting people with dementia and the dementia friends symbol indicate that the associations are committed to becoming dementia friendly
7. Strategic changes are more difficult to put in place. The associations' experiences suggest that strategic changes have to be underpinned by concrete changes in processes and practice.
8. Small housing associations have a role to play in creating local Dementia Action Alliances. The evaluation shows how they can effectively establish and join DAAs and outlines some of the potential benefits.

Chapter 5 presents our overall evaluation. It draws on a variety of measures to compare and contrast the work of the associations against. The measures are:

- Quality of Life Outcomes for and by people with dementia and their carers (see the National Dementia Declaration for England (Dementia Action Alliance 2010).
- Comparison with the characteristics and factors that define a dementia friendly community (discussed in chapter 4 of the report).
- Comparison with steps to improve the design and accessibility including way finding for people with dementia (see the Briefing paper we developed for the Learning Workshop in 2013).
- Comparison with core principles for supporting people with dementia (for the health and social care workforce (Department of Health and Skills for Health 2011).

Conclusions to the report show that the small associations made remarkable progress by all the measures we used. Through a mix of pragmatism and planning the housing associations were able to make deep changes. While it is too early to quantify benefits there is no doubt that there *are* benefits. For example, there are individual case histories of people with dementia whose lives improved. Housing associations staff also benefited from the training on dementia awareness and the opportunities this brought them to support tenants and service users (and their own relatives) better. Most importantly staff are committed and enthusiastic about taking the work further.

Chapter 2: Moving Closer to Being Dementia Friendly

Background to the research report

This report presents the main findings from a collaborative evaluation over a year with four small housing associations who decided in 2013 to work towards becoming dementia friendly organisations. They are Heantun HA in Wolverhampton, Racing Homes HA in Newmarket, Waltham Forest HA and Innisfree HA in London. Sutton Housing Society in London joined in and made the fifth association by providing us with information on their activities.

Although very different, each association is committed to making sure they do everything they can to follow current best practice to support their tenants, other customers and their staff to live better with dementia. Their practical experience has lessons for us all. The report illustrates the changes the associations made and gives their reasons for making those changes. As we explain, sometimes there are good business reasons for working better with people who have dementia, but social and ethical reasons come into play as well.

The associations will continue to play a vital role as we move towards discussing and deciding on other probably more practical outputs from the evaluation.

The report is the latest output then from a programme of research. It has its genesis in a national survey by Quality of Life Charitable Trust (formerly Orbit Charitable Trust) in 2012. The survey aimed to find out how small housing associations were planning to support the growing number of tenants and other customers with dementia.

The survey results suggested that relatively few small housing associations had detailed plans in place, although there was a general interest in developing them. The survey also indicated that small housing associations were keen to learn more about how to improve their awareness of dementia and the services that people with dementia need.

Consequently, the Trust commissioned us to devise a learning workshop in September 2013 aimed at small housing associations on the theme of how they could work towards being dementia friendly organisations. The workshop was a great success. The eight participating housing associations enthusiastically responded to the challenges the workshop presented them and departed with a commitment to implement a range of action plans.

The workshop outcomes informed the Trust's report, launched at the Housing LIN annual conference in February 2014, which provided tools and help to become dementia friendly. It is available for free download at www.quality-trust.org.uk

After the workshop, it was decided to add another strand to the research programme. This involved keeping in touch with the associations and following up the progress of four of them. The final strand of the research (devising other outputs and deciding how best to disseminate the learning) is just about to start.

Pushing on an open door

At the Learning workshop it was clear from the outset that we were pushing on an open door and everyone was keen to share their good practice and learn more. We also encouraged the associations to think about small and low or no cost changes that would benefit people with dementia.

The materials we developed for the workshop were adapted from resources that the Alzheimer's Society and the National Dementia Action Alliance had produced. We also added in resources based on research developed by housing organisations such as Housing 21 and the University of Stirling because they related specifically to living environments. They were relevant for housing associations that were thinking about the friendliness of their sheltered or specialist housing and residential care and design. The resources can be found at www.orbit-trust.org.uk

Most of the associations were engaged in dementia awareness training provided by local Alzheimer's Societies. Some were participating in other initiatives as well, such as, the Cuimhne (or memory loss) campaign run by Irish in Britain to which Innisfree HA were able to give their support and which is raising the awareness for the Irish community about dementia. Racing Homes HA and Sutton Housing Society had Dementia Champions (one in the case of Sutton HS). Racing Homes had invited the Alzheimer's Society to talk to tenants and staff. Sutton HS with primarily sheltered housing stock had colour coded the floors of its sheltered housing blocks to assist people with dementia and they were one of only two housing providers that successfully bid for Department of Health (DH) funds to improve the environment for people with dementia (this was via a bid to DH by the London Borough of Sutton). Waltham Forest HA had carried out reminiscence work with tenants and was eager to do more. It also recently relocated its offices so it is right in the heart of the community it serves. Heantun Housing Association was leading the way in many respects since it was and still is a member of the Wolverhampton Dementia Action Alliance and it was working closely with dementia specialists at Worcestershire University on a dementia adviser pilot. Wolverhampton has also since 2102 been working towards being a Dementia Friendly City.

A lot of good work and good practice was, therefore, going on and looking back it seemed to us that the small associations were just waiting for the opportunity to do more.

What is a Dementia Friendly Community?

The notion of a dementia friendly community is a conceptual approach that acknowledges the role of the community in someone's life – both community in the sense of a physical place and people or the social networks we build around us and to which we contribute. People are often part of several communities, for example, where they live, where they worship, sing, dance or where they visit most often. On-line and virtual communities are also popular and often play a strong role in identify. For example, older people from Irish backgrounds living outside Ireland continue to identify themselves as Irish and will often be part of a wider Irish community. Place on the other hand can be very important to some individuals for example the people who grew up, live in and still identify strongly with Waltham Forest in London's East End.

The idea of dementia friendly communities emerged from debates in the 80s and 90s that challenged prevailing health and social care, employment and other policies particularly those that prevented all citizens from participating in society and having choice and control over how they want to live. The social model of disability, for example, provided an alternative way to consider people who are disabled and contributed to respectful ways of talking about and viewing people with dementia. Using a social rather than a medical approach shifted the emphasis from seeing the person as the problem to seeing the barriers that prevent people from being included as the problem (see Oliver 1996 for a discussion). It also led to discussions about enabling people to live with dementia, to be informed about the type of dementia they have and be able to manage their conditions.

Why the dementia friendly community concept is helpful

The dementia friendly community concept acknowledges the individual person with dementia as a whole person with a past, a future, with a rounded identity who has a life in the community where she or he lives and as someone who both takes from and contributes to the community or communities they belong to.

Research by Kitwood (1997) underlined the importance of "personhood" or those things which uniquely identify us as individual human beings in the communities and social networks we are part of. Kitwood also pointed out that the way we experience our status as people is hugely connected to the connections and relationships we have with other people. In other words other people we know reflect their views of who we are back to us. If we accept Kitwood's approach then it follows that it is deeply important to us to continue to be someone whose unique quirks, talents and personality are known to others. However we live in a society where ageism runs deep and dementia still has a stigma and these experiences discriminate and exclude people. See for example research by the Alzheimer's Society (2007) which reported that 50% of UK adults think there is a stigma associated with dementia. The same research report noted that behaviour towards people with dementia is often condescending and paternalistic. Some people said that they are afraid or upset by certain behaviours associated with dementia such as when people "wander" or they are visibly distressed.

In contrast research by Genoe et al (2010) suggests that living in a supportive and inclusive environment makes positive differences to the lives of people with dementia and Katsuno (2005) refers to the difference that good support, co-operation and encouragement make to people with dementia particularly for helping them hang on to their sense of self and self-worth.

This tiny summary of theoretical research sketches out why dementia friendly communities emerged as an attractive idea. However, they are not beginning to be established as real entities and a number of towns and villages are working towards being recognised as dementia friendly communities. The Alzheimer's Society and the Dementia Action Alliance have led this work and their templates are being used by a variety of communities. . At the centre, most importantly are people with dementia and local Dementia Action Alliances which bring together a variety of businesses, services and people to create active and living dementia friendly places.

Defining dementia friendly communities in practice

The Alzheimer's Society and the Dementia Action Alliance state that:

"A dementia friendly community is one where people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute to and participate in activities that are meaningful to them". (See Alzheimer's Society 2012 Building Dementia-Friendly Communities www.alzheimers.org.uk/buildingdfcs).

To become dementia friendly action has to be taken on 10 key areas. They are:

1. *Involve people with dementia* so that communities are shaped around the needs of people with dementia and their carers from all backgrounds and local areas.
2. *Challenge stigma and build understanding* – work to break down ignorance and increase awareness and understanding.
3. *Accessible community activities* – where organised activities take place specifically for people with dementia and their carers, ensure that they are accessible, appropriate and meaningful. When organised activities are being held planned for people in general make sure they are also inclusive for people with dementia.
4. *Acknowledge potential* – underline the important contribution people with dementia can make to local communities and build on the goodwill of people in most communities to make communities dementia friendly.
5. *Ensure early diagnosis* – because early and accurate diagnosis is so important, encourage people to get access to early diagnosis and encourage health and social care services to adopt integrated person centred approaches to support people with dementia in all settings.
6. *Practical support to enable engagement in community life*- a range of practical support to enable people with dementia and their carers is needed so they can take part in community life and get access to necessary emotional support as well.

7. *Community based solutions.* Different solutions can be found within communities people live in to support them better where they live whether that is in ordinary housing, specialist housing or a care home. It is important to identify ways to enable people to remain in familiar surroundings (if this is their preference) and avoid unnecessary hospital admissions. Another key point about the community based solutions idea is that neighbours and friends as well as people who are on a nodding acquaintance take an interest in individuals who have dementia and their carers/families and aim to support them in small but important ways. The message is that everyone in the community can support people with dementia.
8. *Consistent and reliable travel options* – people with dementia and their carers need to know transport that is reliable and respectful of their needs will be available in a consistent way.
8. *Easy to navigate environments* – inside and out the physical environment can confuse people so it is important to think about the changes that make it easier for people with dementia to get about and implement changes whenever possible.
9. *Respectful and responsive businesses and services* – shops and tradespeople, banks and services should be respectful to customers and potential customers who have dementia. They should all be encouraged to take part in dementia awareness training and be asked to become dementia friends.

Person centred services

Having services that are tailored to the individual and which take account of the person's wishes, likes and dislikes is mentioned frequently in discussions about improving practice for people with dementia. Previous research we carried out for Orbit Charitable Trust (Riseborough and Jones 2012) focused on practical steps to introduce person centred services in a housing association and an Age UK. It also involved service actually trying out various changes including having photo boards in public areas of the staff who work in a specialist housing or residential care scheme including how to contact key people. We found that this simple change enables residents and their families to find out who is on duty and makes them feel more in control of their environment. Other changes involved asking about personal preferences, how people like to have help and how they prefer it to be given and including all of the detail in individual's support plans.

There was considerable interest from the small housing associations in the research on person centred working action research and we noted that they all referred to this in their action plans later.

What people with dementia say?

A 2012 report by Innovations in Dementia provided insights into the experiences of people with dementia particularly their views on the factors that make a difference to them. For example people said how important the physical environment was to them and they talked about their support and social networks as well as local groups they were part of.

Yet, some people said they had stopped doing some activities or even going out because they were worried that they would not be able to cope and they were concerned that others didn't understand or know about dementia. Examples of behaviours and reactions were given. Staff in shops, for example, and tradespeople were said to sometimes be impatient with people who have dementia or talked down to them. People with dementia made it clear that they were hurt and angered by some of the negative behaviours and attitudes they came across. On the other hand people with dementia spoke positively about being welcomed by others and said that positive behaviour helped them to go out more.

The importance of exercise and activity for everyone including people with dementia is referred to in a number of studies. For example lack of exercise is sometimes referred to as an underlying reason for 'wandering'. Not surprisingly then exercise and having meaningful activities are mentioned by people with dementia in the Innovations in Dementia report. People with dementia also commented that they should be asked for their views more often instead of it being assumed that they cannot give reasonable opinions or describe their experiences. They were concerned that people with more advanced dementia were probably not being asked for their views. This is an important point since there is now an accumulating body of research which shows that with the right support most people can give their views and can be engaged. See the research reports from the Joseph Rowntree Foundations' Better Life in Later Life Programme which focuses on how best to ensure older people with advanced and life limiting conditions are asked for their views about their care and well-being, for example, Blood I, (2013).

Taking away the stigma about dementia is also important. People with dementia are often afraid to talk about it and they may be too afraid to ask questions or talk about the subject with the people closest to them. Yet, the National Dementia Advisers pilots for example, indicated that the more knowledge people have around them the less likely they are to be afraid (see the evaluation report by Clarke CL, Keyes SE, Wilkinson H et al DH 2013). Being able to be more open and to share information is sometimes referred to as 'normalising' dementia rather than something to be hidden away or to be afraid of. Having accurate information also counteracts old wives' tales, myths and unfounded fears.

The Dementia Advisers pilots also indicate that people with dementia and their friends and relatives benefit from accurate diagnosis and full and frank conversations on types of dementia and treatments. Having an informed diagnosis early on and being able to talk about what that will mean is essential to continuing to have a good life. For many people it makes all the difference because they can plan the next steps and decided how they want to handle matters such as Enduring Power of Attorney and prolonging life. There are obvious messages for everyone since dementia will affect all of us in some way.

Is it possible to create dementia friendly housing organisations?

It is certainly possible to create friendlier living environments and considerable complementary research is going on that looks at creating friendlier hospital and health settings, friendlier residential care and nursing homes and there is an excellent base to build on for housing organisations. See for example, a report by Andrews and Molyneux for the National Housing Federation in 2013 which draws attention to the need for more specialist housing and support services for people with dementia and sets out the major ingredients for dementia friendly homes. Increasingly there is a convergence of opinion that early interventions work best for people with dementia to prevent crises arising later. Tele care and adaptations are also useful as are befriending and volunteer support for people with dementia and their carers.

Much of the research on housing organisations and the detail on how they become dementia friendly are highly aspirational. Yet we could see that it was theoretically possible for housing organisations to mirror most of the approach described in this chapter for building dementia friendly communities. We also thought they could benchmark and improve their progress so far on being dementia friendly using the checklists we developed that incorporated all the factors known so far that benefit people with dementia. At the first learning workshop we talked through these concepts and ideas with the small housing associations and asked if they thought it was possible for them to create dementia friendly housing organisations. The overwhelming response was yes and there was tremendous enthusiasm to go away and do just that.

Four of the associations allowed us to follow them in detail as they implemented a set of changes taking them along the road towards becoming dementia friendly. Sutton Housing Society, who became our fifth, provided us with information in response to a questionnaire; a telephone interview and several email exchanges which helped us map their journey. We also held a second learning event with all five housing associations to consider the key messages from the evaluation. As a result we have a very comprehensive view of what changes can be made by small housing associations; how they are doing them and why these associations think the results are making them more dementia friendly.


Chapter Three: Starting Points and Changes

What the small HA's were doing before the learning workshop



Involving people with dementia

All had some involvement but saw the need to further develop services and practice led by people with dementia




Challenge stigma and build understanding

All did some dementia awareness training for staff. A couple were actively tackling stigma through training and talks for tenants. Two housing associations each had a Dementia Champion



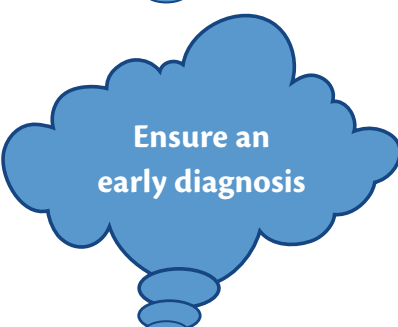
Accessible community activities

All were doing work to promote this - a few were being dementia specific



Acknowledge potential of people with dementia

All wanted to do something – reminiscence & intergenerational projects were happening



Ensure an early diagnosis

All saw this as important – but it's not something they think housing organisations should lead on



All signpost and support people. A couple organised practical help. Sutton HS provided extra training for its Housing with Care Scheme Manager (who was also its dementia awareness champion)



All saw potential because they know their tenants well. Some associations are considering establishing dementia cafes. Others are so well embedded in communities there are many opportunities to talk about people's lives in the community e.g. Racing Homes HA based Newmarket, a horse racing community.



All were familiar with issues but travel for tenants isn't central to housing organisations



Two introduced changes to help people with dementia get around extra care. Several had memory aides on display in corridors to help residents recognise where they are Innisfree HA had a reminiscence film.



Heantun was working on this with other members of its DAA – Dementia Action Alliance

Heantun HA was probably a lot further ahead than the other associations at the start. It has been part of a Wolverhampton-wide initiative since 2102 to be the first dementia friendly city and it is a founding local DAA member. Yet, all of the associations were actively looking to improve their practice, policies and procedures and most had already made changes.

As noted before, Sutton Housing Society is part of a separate dementia friendly project funded by the Department of Health through the Housing LIN. The project will be reported on in due course via the Housing LIN, see [Housing LIN's Focus on Dementia webpages at: www.housinglin.org.uk/dementia](http://www.housinglin.org.uk/dementia)

Becoming Dementia Friendly - Plans by the small housing associations

Heantun Housing Association

1. Strengthen strategic alliances through the Dementia Action Alliance
2. Develop awareness among older people, their families and carers
3. Look at our buildings – how can we make them more dementia friendly
4. Have a pilot regarding dementia advisors
5. Change staff roles and team structures to make the organisation more dementia friendly
6. Look at the activities we provide to see what we can improve on.

Waltham Forest Housing Association

1. Develop a memory wall in sheltered housing and have individual memory books
2. Join the local Dementia Action Alliance
3. Introduce a rota around the schemes to invite external partners to speak to tenants about Dementia
4. Agree a Dementia Champion and roll out training plan for all staff.
5. Produce bespoke guidelines for what makes WFHA a Dementia Friendly Organisation.

In the long term produce a dementia strategy.

Racing Homes

1. Communicate the action plan and the idea of becoming dementia friendly to the whole organisation (to get “buy in”)
2. Roll out the training for all staff + identify a dementia champion
3. Join the local Dementia Action Alliance
4. Make Newmarket a dementia-friendly town.

Racing Homes also noted they wanted to build on the shared memories of its tenants and service users and move towards adopting person centred working to have a better understanding of individuals and their needs.

Innisfree Housing Association

1. Be a founder member of a Brent Dementia Action Alliance
2. Continue to work with Irish in Britain, with their Cuimhne (pronounced Quee-vna) campaign – promoting the culturally specific issues and responses
3. Identify a Dementia Champion for our organisation and invest in training for her/him.
4. Use our Reminiscence Project Film to kick-start more work on reminiscence, memory books/ media amongst our residents and wider London Irish Communities.

John Delahunty CEO Innisfree and Chair of the London small Housing Associations group said he also wanted to arrange for Esther Watts (an inspiring Alzheimer's Society speaker who spoke at the workshop) to speak at a conference in November 2013 for 11 London smaller Housing Associations . Several weeks later John contacted us to say this was all organised.

Sutton Housing Society

1. Draw up a Dementia Friendly Organisation Strategy with a reasonable number of objectives. Present it to our Board for approval (including many actions below.)
2. Based on the above, draw up the implementation plans and roll this out to all staff
3. Brief all staff (17 of us) on the vision of the strategy and plans to raise awareness throughout what SHS vision is to be a dementia friendly place to work and live
4. Investigate if a Dementia Action Alliance activity/group is currently operating in Sutton and sign up, or look at what is involved to take it forward
5. Begin the project with the money from the DOH on 'improving the environment for people living with dementia.'
6. Be a case study on the project for the Housing Lin (note Sutton HS was a DH funded pilot)
7. Once the project is complete (it was completed in July 2014), hold an open day, investigate how all SHS tenants and the local community can use the resources at the scheme (i.e., sensory room)
8. Build into our re-investment and remodelling plans improvements for people living with dementia
9. Monitor the benefits and effects of upgrading our alarm call system, i.e., how many tenants use bolt-on equipment to help them remain independent for longer
10. Monitor our Aids and Adaptations Policy to see if an increase in equipment being demanded to help people remain in their homes for longer
11. Annual training for Scheme Managers, and 2 yearly training/briefing for all staff
12. Train 2 more of our Scheme Managers to be Trusted Assessors.
13. Look to bid for further funding.

No one underestimated the challenges

The associations were acutely conscious that despite their enthusiasm it wasn't going to be easy to take on the extra challenges associated with becoming dementia friendly. They were concerned about many competing priorities including dealing with the fall-out from welfare reforms. They were also facing changes in the funding or direction of their support services due to restricted Supporting People funds. They approached the implementation of any additional challenges with caution.

"We don't want change for change's sake. Work on dementia has to complement and go with the direction of other changes for our organisation". John Delahunty CEO Innisfree HA.

"I have to be sure we have the time and resources to make significant changes".

Linda Milton, CEO Waltham Forest HA.

Since the workshop

All five housing associations have made more progress than they anticipated. The detailed information they provided gives other housing organisations an insight into the changes housing organisations *can* make to benefit people with dementia.



Waltham Forest HA

Within a couple of weeks of the learning workshop Linda Milton CEO and her colleague Cheryl Whittle (Support Services Manager) were adding to the action plan they had started. Linda was very keen to make progress and decided to make time available to lead on it by standing down as Chair of the local welfare reform group. She also involved key members of staff and delegated tasks. Cheryl and Sally Rowe, a sheltered housing officer, are the Dementia Champions for the organisation. Cheryl being the strategic lead while Sally is the operational lead.

Linda was impressed at the learning workshop by Heantun's approach to training which entailed training all staff at all levels in all types of jobs to be dementia aware. Linda decided that this was something she wanted to transfer to Waltham Forest HA. She wanted to ensure that staff was well trained and informed sufficiently to challenge stigma about dementia but this would involve looking closely at the day to day culture and working practices. She suspected that some adjustments would need to be made in order to demonstrate the organisation really did respect and support people with dementia and their carers. For example, the organisation performed very well in terms of monitoring tenant's behaviour and captured a lot of information about their changing needs. However, it wasn't clear if the monitoring and information was sensitive to signs of dementia in a way that supported individuals. Consequently the association audited its practices and processes in a very detailed way and made changes. Within a short time a new and revised action plan was agreed with the Waltham Forest HA Management Board. The action plan continues to be added to and updated.

Waltham Forest HA: The Sunshine Group

Early changes included setting up the Sunshine Group, a regular club for tenants which specifically aimed at being inclusive for people with dementia but involved other tenants as well. Reminiscence sessions were started in the Group from its first meeting in October 2013. Resources used for the Group include the “This is me” book published by the Alzheimer’s Society which gives every tenant the opportunity to present a picture of their lives and the things that were and are important to them. Regular sessions have been held since and the club is popular. People have so far enjoyed sharing their diverse histories and cultures.

Waltham Forest HA: Memory Wall

Ideas around “memory walls” to help tenants identify with something they were familiar with were talked about a lot at the Learning Workshop. Memory walls are typically a display of photos and objects that relate to formative younger days. For example, photos showing the types of fashions for younger people perhaps 50 years ago or photos of people aged 20-30 at the dance hall or queuing for the cinema. The memory walls remind people of fashions and experiences they have in common with others of the same age and prompt people to talk about their experiences. For people with dementia these experiences are often easier to recall than more recent experiences.

Waltham Forest HA designed a memory wall and requested all sheltered schemes to put up notice boards that are capable of being memory walls. A member of staff has the task of ensuring that the memory walls contain useful and relevant information for people with dementia. The memory walls also incorporate materials that people from diverse backgrounds and cultures can associate with as well.

Memory books

The “This is me” books are also being used in one to one sessions by Support Staff with tenants. For people who are living with a developing dementia the opportunity to develop their individual memory books can be a momentous experience.

Waltham Forest Dementia Friends

All Waltham Forest HA staff have become dementia friends and they are very enthusiastic about their roles.



Racing Homes

Racing Homes brings together Racing Welfare, a benevolent charity that provides help for the stud, stable and support staff of British Horseracing and Racing Homes, a registered housing association that provides housing and support for people working in or retired from the racing industry. The association provides housing for people at different times in their racing careers including young people from the age of 16 and people who are very frail or injured. Racing Welfare provides financial help, support, counselling and practical assistance for the stud, stable and support staff of British Horseracing who are facing hardship and difficulties.

Perhaps because work associated with horse racing is very physical and injuries are common, dementia and cognitive impairment are experienced fairly often by the people Racing Homes work with.



Racing Homes – Working towards being person centred

Keith Bovill, Head of Housing and Simone Sear Head of Welfare have worked together closely as individuals but since the Learning Workshop they have made a concerted effort to bring Racing Homes housing and welfare staff together more often than before. Staff from Racing Homes and Racing Welfare now carry out joint allocations and they have a fortnightly exchange of information about tenants and service users so the staff can be sure they share the same information. The organisation is improving how it collects and uses information that is important to the individuals they work with. This is particularly important as the organisation is also improving its out of hours and emergency call systems so they are responsive to individuals and ensure no-one falls through the cracks.

Staff also share information regularly in between meetings and it is seen as everyone's responsibility to assist someone with dementia.

Design changes benefit everyone

Linda Milton pointed out that the design changes benefit everyone and not solely aimed at people with dementia.

“A coloured toilet seat, for example, helps someone with dementia to identify that it is a toilet but at the same time there are benefits for others and there are no negative effects on anyone”.



Racing Homes – Dementia Awareness

Around 50% of the Racing Welfare staff have completed dementia awareness training with the local Alzheimer’s Society and staff are very enthusiastic about the training. It is anticipated that all staff will complete the training and that it will become part of the routine training programme for staff.

Staff are also volunteering to become Dementia Friends so the messages of challenging the stigma associated with dementia are being taken personally as well as professionally.

Racing Homes staff hold meetings with tenants every quarter and they are gradually introducing topics about dementia and dementia awareness into meetings. At a practical level Racing Welfare staff are more aware of the kinds of practical help and support that will make a difference to people with dementia. They have built up a range of improved contacts to enable them to do this although work on this is still progressing.


Racing Memories – the people in racing and training are people’s families

In common with many housing associations Racing Homes aims to sustain people to carry on living in the communities they want to live in. But this has a slightly different twist for horse racing communities with their unique culture. The staff are acutely aware that many of their tenants and service users left home at an early age and the friends, the owners and contacts they made through working in the horse racing industry often became their family and home. Many people also live or lived in tied accommodation so home and work are physically joined.

The links tenants and service users have to horse racing and training also define many people – the work they do/did and the trainers they work or used to /work with are part of an individual’s life story. Racing Homes are acutely aware of how important it is for tenants and service users to be able to talk about their experiences, especially when they are getting older and frailer and if they are developing dementia.

Our living memory walls

Racing Homes works in locations that are synonymous with the British horse racing industry. In traditional horse racing towns such as Newmarket where Racing Homes head office is located, no-one is ever very far from, for example, a Racing Yard or training gallops. Racing towns in this sense have their own living memory walls. Both Keith and Simone commented that having a physical reminder and the social networks that go with a place heavily steeped in horse racing helps their tenants and service users to feel they are still in touch. These strong memories and physical reminders particularly help people with memory loss.



Involving people with dementia acknowledge

Equine assisted Psychotherapy project

Featuring strongly in all the memories and feelings Racing Homes tenants and service users have of horse racing are the horses. Yet it's the horses that it can be most difficult for ex-workers to come into contact with.

Racing Welfare has recently developed a proposal for a new project. Staff are bidding to the Racing Foundation for funding to set up an Equine Assisted Psychotherapy project which would benefit their tenants and service users through linking the project to the Retraining of Racehorses Charity. This would provide close contact with horses, it would be beneficial for the horses and there are elements of cognitive therapy for tenants and service users including people with dementia.

Heantun HA

Heantun has continued to make excellent progress. The housing association benefited from being involved in a Dementia Adviser pilot, part of a nationwide pilot programme organised by the Department of Health (it has now come to an end).

The housing association held a dementia awareness week which they rolled out through the organisation. Staff now lead meetings with sheltered housing tenants to talk about dementia openly and hopefully encourage tenants to see dementia as normal rather than something to be hidden away. They hope in this way to enable tenants with dementia to feel more welcome and encourage more understanding from their neighbours, carers and relatives.

Heantun completed their training programme as anticipated, in partnership with Worcester University and they aim to incorporate dementia awareness training into all future induction training for new staff. They also intend to keep up the training so members of staff have refreshers and access to more training. Staff say it can still be hard to convince some sheltered housing tenants that other tenants with dementia should be supported to continue to live in sheltered housing. The training is the bedrock for giving staff confidence and knowledge so they can challenge stigma and encourage people to get a diagnosis.

A member of the sheltered accommodation staff was seconded to work with health preventative services (Priority Care) at a local hospital. The pilot concentrated on helping people with dementia in hospital and who needed support so they could go home and people who were in earlier stages of dementia but who were in touch with memory clinics. 60 patients were helped as a result of the pilot and Heantun built up valuable knowledge and expertise about the kinds of resources and help available to people both in hospital and in the community. They also gained an insight into what seems to work well for people. There are plans to share knowledge around the housing association.

Heantun members of staff have also volunteered to become Dementia Advisers working to spread their knowledge and awareness through the wider community.

Innisfree HA

John Delahunty CEO has been spreading the word about being dementia friendly not only within his own housing association but as Chair of the small housing associations group in London. Innisfree works closely with the Irish in Britain organisation.

Most recently Innisfree joined with the Cuimhne or 'Memory loss' campaign – a phrase being used instead of dementia which was launched by Irish in Britain on World Alzheimer Day. The

campaign aims to draw Irish businesses, clubs and social organisations together and develop a greater confidence amongst staff and organisers to talk with people who have memory loss problems. The campaign has attracted considerable attention throughout the Irish community in the UK.



Culturally specific and complex

The campaign has helped Innisfree reach out to their tenants and the wider Irish community in London and given them the opportunity to talk about dementia. It has also highlighted the cultural specific nature of dementia experienced by Irish people who emigrated to London and elsewhere and although they often intended to, never returned to live in Ireland. As we say, memory loss is the term being used and this is because many older Irish people find it more comfortable as a conversation opener. Charlotte Curran Irish in Britain's Health Development Worker told us

"There is considerable stigma associated with the word dementia for older Irish people. People can be hiding a lot of sadness and we are very aware of it".

John Delahunty pointed out that the sadness is often related to negative and repressed feelings which people often don't want to talk about. He said that this makes him acutely conscious of sensitivities.

In separate interviews Charlotte and John explained the diverse experiences of waves of Irish workers. While many people emigrated from Ireland for purely economic reasons there were a great number who had no reason to stay particularly young adults who suffered through the punitive Irish orphanage and industrial schools system often run by religious Orders. The shame and stigma of those experiences continue to bring great unhappiness. In later life it is not uncommon for people to feel tortured by memories of growing up. Talking about dementia at all is therefore a complex issue but one that Innisfree was keen to get to grips with. The Cuimhne offers a very useful bridge.

Through the Cuimhne, Irish in Britain and the other members in the alliance supporting Cuimhne have made links with the Alzheimer's Society and they are recruiting people from Irish Communities to become Dementia friends. The key to it all is the understanding of recent living Irish social history.

Given that dementia is so highly charged a subject and there are layers of complexity for Irish communities, Innisfree notes that it welcomes the opportunity to work with Irish in Britain. Both organisations are developing a platform together.

Innisfree: Making our sheltered scheme dementia friendly

The housing association's philosophy is to have an approach that benefits everyone including but not solely people with dementia and their families. The association is acutely aware of the need to use its resources carefully. There are also a number of new challenges and opportunities that the housing association is working with including the need to restructure internally so the organisation can take advantage of new opportunities to develop. Mindful of the competing demands Innisfree engaged Charlotte Curran from Irish in Britain to work on two tasks. The first is to make Clochar Court; an Innisfree sheltered housing scheme dementia friendly in a way that benefits all. The importance of culturally appropriate artefacts and images is central to this. Work has started and it includes talking with tenants.

The second task is to work with Innisfree to develop the association's strategic direction. This involves helping to establish the Dementia Action Alliance in Brent.

Training

Staff at Innisfree have carried out dementia awareness training and the association is looking to develop appropriate and culturally specific packages of training, particularly person centred approaches to supporting people.

Sutton HS

Sutton HS has made very good progress on its action plan. Although the changes that the Society began to make predated both our project and the funding the Society received for being part of a Department of Health programme the additional funding was extremely helpful to them. .

The Society primarily owns and manages sheltered housing and has 11 sheltered housing schemes. It owns and manages one housing with care (extra care scheme). In the housing with care scheme over 50% of tenants have been diagnosed with dementia. There has therefore been an urgent need to respond to their changing needs.



Sutton HS: Environmental improvements

Before 2013 when we started our work, Sutton HS carried out a programme of colour coding in its sheltered housing and its housing with care scheme. Art work was also installed in the housing and care scheme. The top floor includes art works provided by tenants while the second floor includes story walls based on life in London. The purpose was partly to encourage tenants to put their own stamp on the building and to stimulate conversation for everyone including but not solely people with dementia. A spin off is that the colour coding and art works project also provides a good method for people with dementia to find their way around. The art work is a popular talking point for tenants, their visitors and for other housing organisations. Often referred to as story walls they feature amongst other things familiar scenes of London and images from popular culture that many people in their 60s, 70s and older identify with.

"People love the story walls – they have become a real talking point".
(Zoe Macgregor Williams from Sutton HS).

Zoe carried out the research for the story walls and obtained relatively low cost but highly effective posters. Look out for more details about the story walls on the Quality of Life Trust website.

Lighting and equipment

Sutton HS also introduced good lighting and made design changes that they mentioned in their action plan.

In the sensory room, in the housing with care scheme, the Society introduced other changes such as lighting, sound and smell diffusers, musical equipment, bubble walls, tactile wall hangings and massaging and vibrating furniture. A new sensory garden provided additional scope for tenants and their visitors to enjoy the small and feel of a garden outdoors.

Emergency alarm platforms, extra capacity and telehealth/care

Amongst other things Sutton HS upgraded its emergency alarm system making it easier to add on telehealth packages and some limited other equipment. . The equipment is being tried out by people who need it. Sutton HS front line staff participate in assessments in a multi assessment team to ensure that tenants will be able to make best use of the equipment. The purpose is to enhance someone's ability to live independently and or help them through a period of ill health or recovery, for example, when they are recovering after a period spent in hospital.

The association will be monitoring the impact that the changes overall have on people's well-being. The garden and the sensory room are already known to be very popular.

Working with tenants who have dementia

Sutton Housing Society has made the changes it set out to make in its support planning for tenants. As a result members of staff actively signpost people to local services that can support them and they introduce tenants with dementia to specialist local services – such as Avenues.

"We work with Avenues, a local organisation who befriend and support people with dementia and help our tenants continue to do the things they want and live their lives."

Zoe Macgregor Williams (Housing Services Manager).

Sutton HS Training – CPD

In common with all the small housing associations in our follow up study, Sutton HS staff have been engaged in dementia awareness training and this is part of training for new staff going forward. To keep up with the central importance of having person centred services as part of their dementia friendly offer the housing association has encouraged and supported staff to do other training. Staff are encouraged to keep up with their reading on new research and to take advantage of the local authority (London Borough of Sutton) on-line dementia awareness course. This course is central to Sutton HS's refresher training. All staff will be required to complete refresher training within two years of their first training. Dementia education is therefore being embedded into Sutton HS's CPD.

Individual members of staff are really motivated partly by the dementia training and because they can make a positive difference to people's lives. A Housing with Care Scheme Manager for example completed an on-line correspondence course on being person centred for people with dementia.

Plans to disseminate the experiences of Sutton HS

The Housing LIN is working with the DH and Prime Minister's Challenge on Dementia Health & Social Care Champion's Group to capture examples of practice that showcase the impact of dedicated capital funding to transform both existing social housing and develop new purpose-built specialist housing that are 'dementia-friendly'. Further information is available on the Housing LIN's Focus on Dementia webpages at:

www.housinglin.org.uk/dementia

Caveats – dementia and early diagnosis

The small housing associations decided it was not appropriate for them to be actively involved in encouraging individuals to seek early diagnosis. It was not a suitable role for them and they were concerned that it was placing expectations on housing organisations that could not possibly be met. Signposting to sources of information and help was another matter – they were all involved in this to some extent. They also acknowledged that it depended on individual circumstances too. For example if a tenant had a support relationship with the association and wanted to obtain a diagnosis. Yet in the normal tenant and landlord and staff – employer relationship the subject would only arise if individuals sought support and signposting assistance.

Key points from chapter 3

- The five small housing associations demonstrated that it is possible to take most of the ingredients that underpin to the creation of dementia friendly communities and dementia friendly housing and actually apply them.
- The relationships the housing associations made with their local Alzheimer Society and local colleges were vital for bringing in the initial dementia awareness training.
- Training made people want to get involved – many people *chose* to become Dementia Friends
- After initial dementia awareness training the associations have had to find what works best for them in terms of keeping staff up to date and getting involved in additional dementia education.
- The small housing associations have broken new ground – we know much more now about *how* to make changes that are dementia friendly
- We know more about the specific changes that work with diverse communities including multi ethnic communities in East London, people from horse racing backgrounds and people from the Irish community
- Some of the minor design and physical changes to housing stock cost very little but they do need research and staff time in order to be done well
- Changes to front offices and ways of operating so staff, buildings, ways of communicating is dementia friendly cost time but not a huge amount of additional resource.
- Other more far reaching physical changes to the fabric of the housing stock, colour and design changes were embedded into long term refurbishment and upgrading/maintenance plans.
- The small housing associations agreed that any design and service changes had to benefit all tenants *including those with dementia*
- Also through applying for sums of money from Government and other funders e.g. Joseph Rowntree Foundation.
- Some changes are being achieved through working with partners e.g. better support planning and person centred working.

- Small housing associations show very clearly how they can work within their communities of place and attachments in unique ways
- They can achieve a great deal because they know their tenants and service users very well – they can tailor services to meet individuals needs and respond because there is that personal link - it is an advantage over larger housing organisations
- The small housing associations show there is considerable discomfort around the notion of encouraging people to obtain early diagnosis. It is the one aspect of creating dementia friendly communities that cannot be transferred easily.



Chapter 4

Why we changed and how. Embedding operational and strategic change

Some of the Chief Executives in this evaluation were concerned about taking part in an initiative they might not be able to follow through. Yet they overcame their concerns and retained their enthusiasm. We wanted to know:

*What motivated them?
How did they conceive the shift from enthusiastic ideas to making strategic changes that would affect the direction of the organisation?
What if anything did they do to start embedding strategic changes and,
What did they plan next?*

Motivations

Common to all was the desire to support their tenants better. The CEOs and senior staff who worked with us repeatedly gave us the same explanation.

Good business – good ethics

Since they are small organisations they tend to know their tenants very well and that knowledge makes a huge difference to their relationships with tenants. Staff see progressive changes in tenants with dementia and they know about the impacts on them from other events in their lives, for example, from losing their partner or good friend.

“Knowing about dementia is useful for us all in life. It’s good business sense but good ethics too”
(Linda Milton, Waltham Forest HA Chief Executive).

Keith Bovill and Simone Sear from Racing Homes who had several personal stories about tenants they knew well were also conscious of the need to prepare for the future:

*“We have to start preparing – there will be more people with dementia and we **want** to do more”.*

John Delahunty reflected on research by Irish in Britain which found a disproportionate number of people in London from Irish communities who had dementia. His motivations were linked to serving the Irish community.

It IS personal

There was a personal story in every housing association. Almost everyone knew someone with dementia including close members of their families. Having the dementia training made people have personal conversations and encouraged members of staff to talk about the situations they had encountered. Everyone agreed that personal knowledge about dementia was important.

One comment summed it up:

“It could be me. I have a stake in the future in this”

Training – a revelation

It seemed that the more people knew about dementia the more enthusiastic they became. All the small housing associations were convinced about this.

Cheryl Whittle from Waltham Forest HA explained, for example, how members of staff felt empowered to act as a result of their dementia awareness training because it helped them identify and understand some of the behaviours they had seen from people with dementia. The difference this made to members of staff was transformational. Cheryl described how, for example, members of staff shifted their perceptions from seeing a tenant's behaviour as difficult and uncomfortable to deal with to an instance that needed to be understood from that person's point of view in order to help support her or him better.

Cheryl went on to explain how staff meetings have changed. Members of staff share information about their tenants and service users in a very different way. The emphasis is on supporting as much as possible and finding the personal solution has become the *raison d'être* amongst staff.

Racing Homes Simone Sear had similar experiences. She noted that staff benefited enormously from the dementia awareness training both personally and professionally.

Sutton Housing Society noted that the training was a starting point for their staff (although they started their training well before our project started). The Society noted how important training is for building up people's enthusiasm as well as their knowledge. For example, tenants who are diagnosed with dementia usually need to come to terms with this and then may need to talk the future over with their families. Being able to signpost and support families through the process is important. For many this will involve considering a Power of Attorney and what this means. The staff have had to learn not only how to recognise and work out how to best support the person with dementia but also to consider the best way to support them in the future. All of this calls for good knowledge in order to do accurate signposting including information on where to go for help as people deteriorate and their needs for support become more complex. In addition staff are building up knowledge on subjects such as where to get legal help with Powers of Attorney¹ and Living Wills.

Still learning

Everyone told us they are still learning and intend to go on learning. The moral is that being dementia friendly is only the start.

Heantun told us that their training has exposed some difficult issues in that whenever they talk to tenants they tend to say that if they develop dementia they want to stay living where they are if at all possible. However the same tenants are sometimes less understanding of other tenants who are confused or distressed because they have dementia. Staff are working hard to change some tenants' prejudices and expectations. Discussions have to be held in a respectful way, which take into account the views of everyone. Reading between the lines we suggest that these are pretty sophisticated skills about getting along together which most people have never had to learn.

¹ Power of attorney takes three forms – ordinary, lasting and enduring see <http://www.ageuk.org.uk/money-matters/legal-issues/powers-of-attorney/>

Innisfree HA told us that they have had to come at the whole subject of dementia in a sensitive way – they have had some training for staff from the Alzheimer Society but it was very important to find a way forward that suited Innisfree’s predominantly Irish tenant base. It was also important for Innisfree to demonstrate that the benefits would reach the wider Irish community.

“We are always conscious of a wider community and we have to be smart about getting the most value we can”
(John Delahunty CEO Innisfree)

Racing Homes said that for them there is still a great deal more to learn about finding the right approach that works best for their tenants and service users. They think that bringing the staff resources together better and doing more work jointly has brought positive differences. They also noted that the training from the local Alzheimer Society has made staff more confident about talking with groups of tenants about dementia and how they can support each other.

Operational practices and processes

We have commented on some changes already. For example, Racing Homes introducing joint allocations procedures so that Racing Welfare and Racing Homes consider tenant and service user needs in a person centred comprehensive way.

Waltham Forest HA has probably developed the most far reaching changes in its operational practices and processes. Following the learning workshop we held in 2013, Waltham Forest HA audited their processes and amended them. They then imported the results and proposed changes into an updated action plan that was adopted by the Management Board.

Extract from Waltham Forest HA Action Plan – Dementia Friendly Organisation

What we do now	Where are the gaps
<p>Contact with family at crisis stage (mainly)</p> <p>Sheltered housing tenants know their main contact is the Supported Housing Officer. Relatives also tend to know this.</p>	<p>General Needs tenants – build better contacts with the family members before crisis if made aware of the situation</p> <p>Action to address this: Article in the newsletter had been done for all tenants advising them of the contact name at head office if they need sign posting to services</p>
<p>Assist/advice/guidance in maintaining daily living for people with dementia e.g. letters, appointments etc.</p> <p>All staff are able to provide information. Further information and useful resources is available for all on dementia and continuing to manage to live independently in the staff sign in area independently in the staff sign in area</p>	<p>Information is available at reception and the staff area in our main office and in sheltered housing schemes to allow staff and tenants to have access in private to information</p> <p>The sunshine group also has information given out on a monthly basis to the tenants</p>

Heantun similarly changed its processes for support planning – the key to this was introducing a person centred approach. In addition Heantun trained some members of staff to become ‘trusted assessors’ although they pointed out that despite this it was still difficult for some local authority and health staff to accept their assessments. Heantun see it as a work in progress.

Innisfree believe that while the dementia awareness training was a big step forward they need to build on this and develop something that they can apply in their support planning. CEO John Delahunty commented that the organisation would benefit from an assessment tool that would produce tailored plans for tenants living in their general needs housing or people who (potentially) could buy in support from Innisfree.

“The training is really useful but it’s not enough – we want if possible to produce tailored plans that work for individuals”.

Sutton Housing Society is developing new aspects of support planning, working with tenants and their carers/ relatives to find the best way to support the person with dementia and carers. The person with dementia remains the most important person in Sutton’s approach to support planning.

Everyday Practice

During the course of the research for this report we visited offices that the housing associations work from. We looked amongst other things for evidence that the organisations were demonstrating their interest in becoming dementia friendly. All of the organisations we visited had posters, the dementia friends’ symbol and other helpful visual signs on show. We noted that staff answering telephone queries are alert to the fact that some of their service users and potential service users may or actually have dementia.

At Waltham Forest HA we were told about some tenants who have dementia and regularly visit the office. Staff have completely changed the way they respond to those tenants. Linda Milton and Cheryl Whittle explained:

“Typically ‘Ted’ upstairs would come down to the office 3 or 4 times a day to report a minor repair. The staff were very helpful to him and pleasant but to be honest they probably just processed the repair request and left it at that. But now they will remind him that he has reported it and will explain repeatedly so he understands. They will also take an interest in him and his wife and ask how things are so we know if there are problems. Now it’s everyone’s business (to support people with dementia) and not just the support staff.”

Using intelligence and information better

Simone Sears and Keith Bovill from Racing Homes also told us about instances where living and working locally as they do brings a natural opportunity to listen out for how a particular person is coping. The organisation has completely redesigned how it responds to out of hours and emergency alarm calls in order to provide tenants and Racing Welfare service users with a better support service. They have carefully looked at the information they hold about tenants and service users and are working out how this could be used to make sure people get a personal response.

Waltham Forest, Sutton HS and Heantun also look at the information they have about tenants and they are using this to understand their tenant and service users better. For example, if someone is repeatedly using the emergency alarm service or the organisation is being contacted by the police because an individual is lost the housing associations will actively approach the tenant to see if he or she needs support and advice or information.

Moving from enthusiastic ideas to strategic changes on future direction

It is still very early to comment on this but the evidence so far is that some of the small housing associations decided to make a strategic change of direction. They did this in several ways including:

- Presenting the action plans to their Boards and having the plan adopted
- Deciding to establish or join the local Dementia Action Alliance
- Adapting existing or designing new policies

Presenting the action plan to their Boards and getting it adopted

Racing Homes HA

Keith and Simone introduced all members of staff to the Racing Homes Dementia Plan and progress against it is reported regularly at Board meetings.

Waltham Forest HA

The action plan is referred to regularly at Board meetings and specific objectives are part of the Chief Executive Linda Milton's, annual appraisal. The housing association intends to develop a dementia strategic plan.

Innisfree HA

The action plan has been adopted by the organisation and progress is reported on regularly to the Board. There has been mixed progress but overall Chief Executive John Delahunty is pleased about the general direction of travel.

Heantun HA

Heantun HA is in the process of a bigger change since it is merging with Accord HA and will be a wholly owned subsidiary. Heantun has had a strategic plan in place for some time and Bill Laybourne (Joint Service Director) anticipates that work will continue to develop this.

Sutton Housing Society

The Society adopted its action plan and is working towards developing a dementia strategy. It is focusing on the areas of work Sutton HS anticipated at the start and new ways to support people with dementia.

Start with what you can do and work with what you have

The five small housing associations in our study are pragmatic. They are used to juggling priorities. Their first actions once they had decided to move forward with their action plans was to look at the changes they could make immediately. A key priority was training. The second most common action involved examining their existing practices and processes to see what could be done quickly to improve the outlook for people with dementia. The third most common change involved strategic shifts although all of the associations recognise that this level of change takes longer and involves more resources.

Joining or establishing local Dementia Action Alliances

At the Learning Workshop Esther Watts from the Alzheimer's Society and Jeremy Porteous, Director the Housing LIN spoke in favour of the national and local Dementia Action Alliances (DAAs). There were it seemed particular benefits for housing associations interested in forming closer relationships with health commissioners many of whom are members of local DAAs. However, DAAs are not talking shops they are mature partnerships where members agree to make a series of changes and pledge active contributions in order to help create a dementia friendly community.

All of the small housing associations were interested in DAAs and most wanted to join one or were prepared to help establish one if there wasn't a local DAA yet in existence. The discussion was made more accessible because the speakers were willing to share real experiences and because Heantun was already a founding member of its local Wolverhampton wide DAA.

Since the workshop Waltham Forest HA and Innisfree HA have made particular progress.

Waltham Forest HA

Linda Milton CEO was initially concerned that she could not afford to devote sufficient time to helping establish a local DAA. In order to make time Linda stepped down from heading a welfare reform group. Linda said that for Waltham Forest HA this was a major undertaking and one that could make real changes to people's lives:

"It isn't like other partnerships where there is mostly talk – this is a big commitment".

Linda has in fact taken a lead role in establishing the DAA and it has taken six to seven months of concerted work to get to its first meeting. A formal launch of the DAA is planned for October 2014.

So far the DAA has recruited a wide range of partners including the local authority, the Well Being Board, Health Watch and the Carers Association. To find out more see http://www.dementiaaction.org.uk/local_alliances/6592_waltham_forest_dementia_action_alliance

Innisfree HA

Innisfree HA has been a catalyst for establishing its local DAA in Brent. As noted before, CEO John Delahunty engaged Irish in Britain's' Charlotte Curran as a consultant to take the DAA forward and the Brent DAA recently held its inaugural meeting. Members of the DAA currently include Brent's Director of Adult Social Care, a trustee of the local Carers Association who cared for his parent with dementia and a woman diagnosed with early onset dementia.

Racing Homes

Racing Homes is working towards a local and organisation wide solution. Immediately after the learning workshop Racing Homes intended to spread the word across the organisation and hopefully come up with a plan that would map onto Racing Welfare's regional officers in England. However that hasn't been achievable and it is likely that instead of being able to form DAAs or join existing DAAs as a strategic choice at the same time progress is going to be slower.

Simone Sear Head of Welfare and Keith Bovill Head of Housing explained that they were anxious not to lead too much from the centre. Simone in particular is keen to see cultural changes take place and she strongly believes that it is essential to encourage staff to take a lead themselves. However, Keith and Simone reflected on their experiences so far and are exploring an incremental way forward to establish a local probably Newmarket or sub East Anglia DAA. For example, Keith noted that it is possible to work up interest and support by talking to local businesses and shops. Racing Homes is very well known locally and Keith and Simone know most of the local businesses so they have a head start.

In 2013 when we started our work and members of staff from Sutton Housing Society came to our first learning workshop Sutton did not have a DAA. Now it does and the Society is considering if it can join and find sufficient staff resources to do this.

Policies

Dementia friendly policy for staff

At the Learning Workshop we talked about the work of the National Dementia Action Alliance to involve employers in responding to the dementia challenge, including large high street names. This theme was taken up by small housing associations and is being pursued in several different ways.

Several of the housing associations know members of staff who have been or are doing their best to support parents and step parents with dementia. Not surprisingly then all of the associations are interested in the possibility of developing appropriate dementia friendly policies for staff. It isn't straightforward and in most cases existing policies covering staff absence or flexibility over working hours need to be examined to see if they fit or need some amendment. For small housing associations there are additional problems because there are fewer core staff compared to larger organisations. Yet there is some room for manoeuvre.

Waltham Forest HA has made particular progress on this and has included being dementia friendly to staff in its action plan.

Sally Rowe, a Waltham Forest HA sheltered housing officer, described the difference that having a dementia friendly employer has made to her. She said that not only has the additional training and know how added to knowledge and skills it has also helped her personally. Her step mother has developed dementia and she is able to talk through the problems and issues she has with finding the right kind of support for her step mother and she doesn't feel so alone. She told me she feels it's much easier at work now because she isn't ashamed to talk about the situation she is experiencing. She also thinks that having knowledge about dementia makes it easier to talk with her step mother about the support she needs and the future.

Linda Milton explains the rationale for adopting a dementia friendly policy for staff:

"I think it's very important to be open and to make the policy of being dementia friendly run through the whole organisation."

Key points from chapter 4

1. Motives for involving the organisation were a mix of ethical and social as well as thinking about future business and needs.
2. Most of the organisations began with their action plans and got support for a whole organisation change from their Boards of management
3. The associations usually started by addressing the easier targets first.
4. Training brought many benefits and was responsible for staff looking afresh at their everyday practice and processes.
5. Small but highly specific changes brought big changes e.g. changing the way support planning was done so that the person with dementia is at the centre.
6. Changing reception areas and display areas so they include materials about supporting people with dementia and the dementia friends symbol indicate that the associations are committed to working towards being dementia friendly
7. Strategic changes are more difficult to put in place. The associations' experiences suggest that strategic changes have to be underpinned by concrete changes in processes and practice.
8. Small housing associations have a role to play in creating local Dementia Action Alliances. The evaluation shows how they can effectively establish and join DAAs and outlines some of the potential benefits.

Chapter 5 - Evaluation Conclusions and Next Steps

Evaluation

Our evaluation is based on a comparative, fairly rigorous analysis but it is obviously time limited since we have only been able to follow the progress of four housing associations and get some insights into the work being done by Sutton HS for a year. All the same the indications are powerful.

We used four measures of comparison:

- The individual housing association action plans compared to what they actually achieved and their reflections on the benefits
- A comparison of the actions taken by the housing associations with the Quality of Life Outcomes for and by people with dementia and their carers
- A comparison of the actions taken by the housing associations with the steps that define dementia friendly communities
- A comparison of the principles identified in the actions taken by the five small housing associations with the principles identified for skilling up the health and social care workforce to be dementia friendly (see DH 2010).

Progress and achievements compared to action plans

Chapters 3 and 4 show that compared to their action plans most housing associations have exceeded their objectives and progress is still being made on some objectives. Along the way all of the associations have learned a great deal and their enthusiasm and commitment are still strong. The amount of progress made in less than a year (at the time of writing) is remarkable

Good practice on dementia friendly design, accessibility and way finding

There is already a good body of evidence on the design factors that assist people with dementia to live as independently as possible including help to find their way about. In the briefing paper and check lists we prepared for the Learning Workshop we noted that principles for designing dementia friendly specialist housing and care settings are available from a number of sources. They include the leaders in the field the Dementia Services Development Centre at the University of Stirling who have developed training based on evidence they have gathered on what works best with people who have dementia. Their training for carers and housing providers includes some simple steps to enable people to self-care and support them with some simple adaptations and changes so people can continue to do things for themselves as much as possible. Steps include improving the lighting so people can see better, putting easy to read notices on appliances and doors reminding the individuals about the need, for example, to keep the fridge closed or the time they should eat. Also responding to the needs people have about surfaces including mirrors which sometimes arise because distortions occur in people's vision particularly people with Alzheimer's. Colour coding floors so people know which floor they are on or having

memory aides such as way finding so they can work out their location, are also helpful. There is a long list of useful changes that can be made to help people for more information see <http://dementia.stir.ac.uk/>.

Quality of life outcomes for and by people with dementia and their carers

Seven quality of life outcomes that people with dementia and their carers want to see come to pass were expressed in the National Dementia Declaration for England (Dementia Action Alliance 2010).

9. I have personal choice and control or influence over decisions about me.
10. I know that services are designed around me and my needs.
11. I have support that helps me live my life.
12. I have the knowledge and know-how to get what I need.
13. I live in an enabling and supportive environment where I feel valued and understood.
14. I have a sense of belonging and of being a valued part of family, community and civic life.
15. I know there is research going on which delivers a better life for me now and I hope in the future.

We believe the evidence shows that the housing associations set out to support and work towards the best quality of life outcomes for people with dementia and their carers. Most importantly they recognised that people with dementia have to be at the heart of any service design and support plan. Their actions are highly consistent with the outcomes.

Compared to the actions that define a dementia friendly community

Chapter 4 presented further details about the processes and practice that are necessary to underpin a strategic change. The chapter also gives some insights into how strategic changes are being made. There is a close match between the actions being taken by the housing associations and the dementia friendly community steps – in other words progress is all in the right direction under the right headings.

The best practice being developed by the associations compares remarkably well with the principles produced for the health and social care workforce which were prepared using the national Dementia Strategy (updated 2010 DH) and the Dementia Declaration (2010). Particularly noticeable is the commitment to ensuring that all staff support, value and respect people with dementia and their carers and,

Compared to core principles for supporting people with dementia (health and social care workforce)

With one major exception we found a synergy between the principles identified as being important for health and social care staff and those being followed in the five associations.

The small housing associations did not believe it was appropriate for them to become involved in actions around the diagnosis of dementia.

The core principles identified by the Department of Health for health and social care are:

- Principle one: Know the early signs of dementia
- Principle two: Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stages.
- Principle three: Communicate sensitively to support meaningful interaction.
- Principle four: Promote independence and encourage activity.
- Principle five: Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.
- Principle six: Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
- Principle seven: Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
- Principle eight: Work as part of a multi-agency team to support the person with dementia.

(Department of Health and Skills for Health 2011)

Common core principles identified in the practice of the five housing associations

Principle 1: Support, value and respect people with dementia and their carers.

Principle 2: Train all staff to know about dementia and its signs so they can tackle stigma and support people with dementia better.

Principle 3: Support people to get early diagnosis because this helps them receive information, support and treatment at the earliest possible stage.

Principle 4: Communicate sensitively so everyone including people with dementia can take part and understand

Principle 5: Promote the independence of people with dementia and their individuality, encourage activities that people can do rather than those they can't and make positive efforts to include people with dementia

Principle 6: Recognise the distress and confusion that people with dementia experience and encourage all staff to take time to help customers deal with their anxiety and to understand what is happening around them

Principle 7: Encourage tenants and other customers to become more aware about dementia and understand how important it is to support each other.

Principle 8: Consider how to better support members of staff who are caring for people with dementia or who may be developing dementia themselves.

Principle 9: Work in partnership with other agencies to support individuals with dementia, their carers and relatives.

Learning more about the contribution of housing organisations

Housing organisations clearly have a great deal to contribute to making communities dementia friendly. The evaluation provides valuable details on how small housing associations can contribute to wider dementia friendly communities. There are useful pointers here for any other association that wants to join in a local dementia challenge. There are lessons and examples too for any association that is considering contributing to a local Dementia Action Alliance.

Housing associations can and do contribute very usefully to local DAAs – the study provides some evidence on this.

Knowing your territory, your business and your customers

Yet the importance of responding and adapting to the particular locality and to particular customers is also highlighted in this evaluation. Small housing associations have a great advantage compared to their larger counterparts because the staff are usually on first name terms with most tenants and service users. They see minor changes in a tenant's well-being and they often know the tenant's family and friends.

Small associations have a local appeal but they also have to work hard to maintain the local appeal and continue to move forward. There are new opportunities for small housing associations to develop local links with health commissioners and Well Being Boards and these small housing associations are testing the waters. We will see how they fare.

Next steps

There are strong indications that the five housing associations are committed to making long lasting changes.

Waltham Forest HA intends to go on embedding changes and transforming the organisation. They are working towards a full blown dementia strategy. Innisfree is committed to making strategic and deep changes. It is also committed to providing wider benefits for the older Irish community in London. Racing Homes are committed to taking their actions further through their dementia strategy. They are researching different options for supporting tenants and service users better together with its charitable arm (Racing Welfare).

Heantun continues to be at the front of many actions that housing organisation can take to become dementia friendly and they have an exciting future in their merger with the Accord Group. Sutton Housing Society will continue to develop its practice and will share the learning via the Housing LIN, from the Society's work to improve the outcomes for all older tenants including people with dementia. .

Finally – benefits

The associations made new partners and developed new ways of looking at the way they design and provide services. Through the work to develop themselves as dementia friendly organisations they have met challenges and enjoyed them. The experience brought staff together and continues to enthuse them. Perhaps most importantly of all though the housing associations in our study report that they do actually make a big difference to people's lives by including people with dementia.

It is too early to quantify the benefits from becoming dementia friendly but each association is beginning to amass the numbers and the evidence. Individual stories about the benefits to individual tenants and their families were given frequently and the satisfaction this provided for members of staff was obvious.

There are opportunities too for new business –the small associations are developing new relationships with a range of organisations through their work to work towards being dementia friendly including health commissioners and key partners. The individual associations are also more visible to the general public through their work for example to establish Dementia Action Alliances.

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<http://www.orbit-trust.org.uk/research-project/>

Outputs by authors included:

- Phase 2: Creating Fit for Purpose Organisations. Report and Recommendations.
- Practice Papers
- Resources Pack
- Literature review

