

Becoming a dementia friendly organisation

Summary Report
May 2015



Foreword

We want to be a dementia friendly organisation.

The ‘Prime Minister’s challenge on dementia 2020’ was published earlier this year. Guinness is committed to rising to that challenge, and to the aim that England should be ‘the best country in the world for dementia care and support, and for people with dementia, their carers and families to live.’

We provide homes, care and support services to thousands of households across the country, many of them older people. The range of our services means that we are particularly conscious of the need to think about how we support the integration of health and care services. This includes the role that we can play by helping more of our customers to be able to live independently for longer in their own homes, particularly for those living with dementia. We want them to be able to live well.

We carried out this research project because we needed to understand how many of our customers are in households where there is somebody living with dementia. We need to be clear what becoming dementia friendly for those customers meant to us as a business.

There are many initiatives and examples of good practice in customer service and property design which we can learn from. Some of those are referred to in this report. But we need to understand not only which initiatives will work, but also what we need to change, and what the benefits are for our customers. We want to make sure that the changes we make are the right ones, and have a real, positive impact for people living with dementia.

Simon Dow
Chief Executive,
The Guinness Partnership



Introduction

The Guinness Partnership aims to become a dementia friendly organisation so that we make a difference for customers¹ living with dementia.

This report provides a summary of the findings from a range of activities designed to answer the following questions:

- Why is dementia important?
- What is the scale of the challenge for Guinness? How many customers are likely to be living with dementia, and where are they living?
- What does research suggest a dementia friendly housing, care and support organisation should look like? What are the characteristics of dementia friendly services and homes?
- Where is Guinness now compared to this picture of 'dementia friendly', and what needs to change?
- What should be done to transform the Partnership so it becomes more dementia friendly?

This summary report sets out how Guinness tackled these questions, and what it is doing as a result. The report has been informed by a project undertaken by The Institute of Public Care at Oxford Brookes University between December 2013 and September 2014.

¹ The term 'customer' is used to describe all those living in Partnership properties and/or receiving housing, care and support services from the Partnership, regardless of tenure of housing.

Why dementia is important

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. All types of dementia are progressive; this means that the structure and chemistry of the brain become increasingly damaged over time.

Each individual with dementia is likely to experience it in differing ways, and hence present with different changes in ability and behaviour.

Dementia has an impact on the individual living with the condition, on their families and carers, on local communities, and on demand for public services. There is a significant lack of awareness of dementia within society, and often a stigma attached to it. Individuals with dementia describe the need to feel valued and supported, with sufficient and timely advice and information available, and services which respond to their individual needs. Carers also need advice and information, as well as emotional support.

It is suggested that the impact of dementia costs on average £19 billion a year; for example an estimated 25% hospital beds are occupied by people with dementia.²

People living with dementia say they want to be supported to live at home, and national policy supports this. For providers of housing, care and support services the challenge of providing dementia friendly services is an important one.

Given the numbers of people likely to develop the condition themselves, or be a carer of someone living with dementia, it makes good business sense to understand what being dementia friendly entails and to make the changes needed to ensure that they are offering services which can respond to individual need. Often this is more about providing good customer care in existing services to all customers, and particularly more vulnerable customers, rather than developing a range of new services.

Prevalence:

The Department of Health estimates that there are approximately 670,000 people in England living with dementia, and that this number will double in the next 30 years. There are an estimated 550,000 carers of people with dementia.²

² Dementia: a state of the nation report on dementia care and support in England (2013). Department of Health

The context for Guinness

What do we know about our older customers?

- *There are approximately 17,000 people over the age of 65 receiving our services.*
- *Looking at a sample of six local authorities, the proportion of customers who are older people varies from 17% – 44%. This level of variation is likely to be repeated across the areas where we operate.*
- *Although we provide specialist housing and other services for older people, the majority of older customers live in general needs rather than specialist housing.*

What do we know about our customers with dementia?

- *Estimates suggest that there are likely to be more than 1,000 older people with dementia receiving our services.*
- *Whilst the pattern across the country varies, approximately one third of these will be living in general needs housing.*

What we did

The national population prevalence of dementia from an original study in 1998, updated in 2013,¹ suggested 6.5% of the population aged over 65 would be expected to have dementia, with a split by gender. These national rates were applied to information held about the ages and gender of our customers.

Where ages were not known estimates were made using proportions of population groupings based on known ages, and information about the numbers of older customers from minority ethnic communities.

¹ Matthews, Arthur et al: A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II (CFAS)

What we found about older customers generally

We have approximately 17,000 people over the age of 65 either living in our properties or receiving our services. We have nearly 7,000 homes for older people (various forms of sheltered housing and extra care housing) out of a total of nearly 60,000 homes.

The profile of these older customers varies across the different regions, but there are a number of key findings:

- There is currently a large number of 65–74 year olds, many of whom live in general needs housing, (see *Table 1*) but this age profile is likely to change over time given the policy drive to enable people to remain in their own homes, and the known preference for people not to have to move as they get older. This means that the nature of services provided into general needs housing will become increasingly important if customers are to be supported to live independently.

- A higher percentage of the older age groups is living in specialist housing, and customers receiving care at home and residential care are also older. These specialist services are likely to have more customers living with dementia, potentially in the more advanced stages of the condition.
- There are relatively low numbers of older customers from black and minority ethnic (BAME) groups older, particularly in specialist older people housing, although there is a higher proportion in the South and London than in other areas.
- The proportion of older BAME customers is important because of the potential for a different prevalence rate within minority communities (for example because of risk factors such as high blood pressure or diabetes) and because of a potentially different experience of support from dementia or other services.

What we found about customers with dementia

Dementia becomes more likely as you age, and there are also different prevalence rates for men and women. The modelling for Guinness indicates that there are approximately 900 – 1,100 people living with dementia in our homes.

As many of our oldest customers are receiving specialist services, it is not surprising that many of the people with dementia are thought to be in specialist housing, or receiving specialist services. However, we estimate that about 300 customers with dementia are living in general needs housing, and about 100 are living in leasehold properties.

As many of the over 65's living in general needs housing are amongst the younger age group, it is quite likely this figure of 300 will increase over time as this group ages.

Table 1

Partnership	65-74	75-84	85+	Total over 65	Estimated number with dementia
General Needs Property	4136	1972	700	6808	299
HOP	2661	2249	1406	6316	406
Leasehold	781	585	323	1689	98
Total	7578	4806	2429	14,813	803

The distribution of customers estimated to be living with dementia is:

- 55% in our north region (compared with 45% of our housing stock)
- 30% in our west region (compared with 25% of our housing stock)
- 15% in our south region (compared to 30% of our housing stock).

The type of housing it is thought these people are living in also varies by area, but in each case a significant number are living in general needs rather than specialist older people housing.

We looked at six authorities where Guinness has the largest number of homes to understand in more detail the prevalence for specific areas (see *Table 2*). This highlighted the level of variation between local authorities in terms of the age profile of customers, and where they are living.

What we concluded

An estimate of the number of Guinness customers with dementia which is based on prevalence rates will not be precisely accurate, but does provide the context for understanding the challenges of becoming a dementia friendly organisation.

This approach suggests that there are likely to be at least 1,000 customers living with dementia.

Whilst these estimated numbers are relatively small as a proportion of all of our customers, the challenge of living with dementia for an individual and their carers means that being able to receive dementia friendly services is likely to make a significant contribution to that person's ability to live independently.

There is significant variation across the Partnership in terms of the age profile of customers, and therefore the likely presence of dementia. This variation will need to be taken into account when considering specific dementia initiatives, and, given the proportion living in general needs housing, these initiatives need to be accessible to all customers, not just those living in housing for older people.

Table 2

Local authority	Residents over 65 by type of housing				Estimated number with dementia
	General Needs	Housing for Older People	Leasehold	Total	
Manchester	534	171	33	738	31
Havant	689	930	43	1662	90
Milton Keynes	358	67	381	806	35
Sheffield	252	240	87	579	33
Rochdale	320	247	23	590	34
Hackney	251	46	11	308	15

What ‘dementia friendly’ looks like

What people say is important

Dementia affects individuals differently, but there are typically three key stages in its development as typified in the progression of Alzheimer's:⁴

Early stages: Very minor changes in a person's abilities or behaviour, commonly involving loss of memory for recent events. At this stage the focus for carers, family, friends (and professionals) is to maintain independence and enable a feeling of self-worth; planning for the future is very important.

Middle stages: As the disease progresses, changes in behaviour become more marked and the individual is likely to need more support to help with day to day living activities. At this stage an assessment for additional support, if it has not happened earlier, may be appropriate both for the individual and their carer. This could include both health and social care, and involve formal and informal support.

Later stages: On average people with Alzheimer's disease live for eight to ten years after their symptoms begin, although clearly this varies. In the later stages the person will need more help, and become dependent on others for nursing care.

People living with dementia have given very clear messages about what is important for them and the quality of their life, and have described this in the form of a number of outcomes they are seeking:⁵

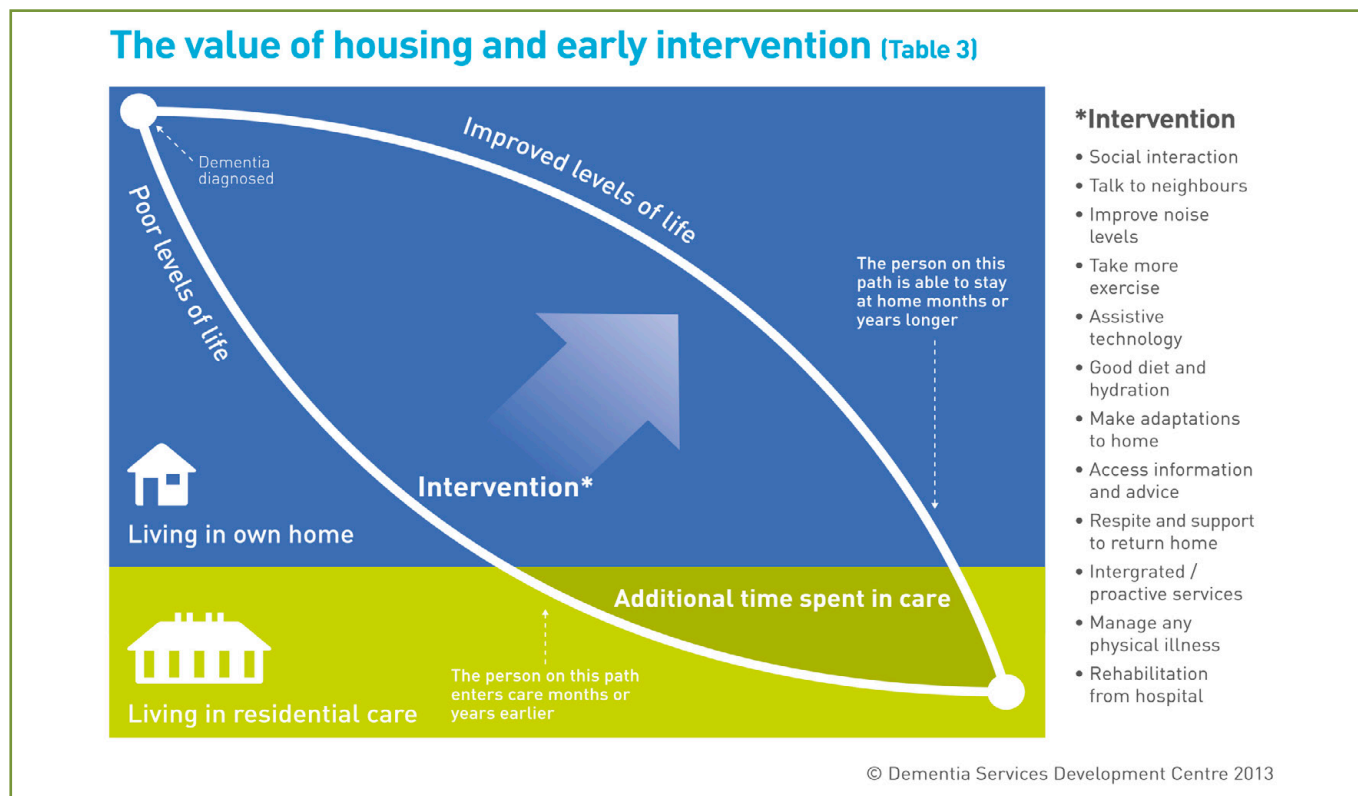
- *“I have personal choice and control or influence over decisions about me.”*
- *“I know that services are designed around me and my needs.”*
- *“I have support that helps me live my life.”*
- *“I have the knowledge and know how to get what I need.”*
- *“I live in an enabling and supportive environment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

Carers also describe the importance of support particularly at the key stages in the development of the condition, including advice and information, signposting to appropriate services, and support to maintain employment, as well as practical help with the day to day care they are providing.

4 The progression of Alzheimer's disease and other dementias, (2011) Alzheimer's Society. Although this material describes Alzheimer's this progression process may also apply to other forms of dementia.

5 <http://www.dementiaaction.org.uk/nationaldementiadeclaration>

What research suggests 'dementia friendly' looks like



Housing and housing related services can make a significant difference to the quality of life for people with dementia and their carers. This includes enabling people to stay in their homes for longer.⁶

We have developed a picture of what dementia friendly looks like through reviewing published research and talking to a small number of housing providers about the work they are doing to support their customers with dementia. There are few formally evaluated examples of good practice, however a judgement has been made as to whether examples are likely to contribute positively to outcomes for older people living with dementia and so have been included for consideration.

In some areas there is little experience of what dementia friendly could look like, but applying some general characteristics has enabled us to suggest changes that could be made and tested with customers for their impact.

We have mapped service characteristics against what we know is important at each stage of the condition for the individual living with it, and so have developed a picture of what a 'dementia friendly' housing, care and support organisation looks like.

6 National Housing Federation (2013).
Dementia: Finding Housing Solutions, page 14

The experience for the individual	The service characteristics needed as a response	A selection of practice examples ⁷
<p>Awareness of dementia:</p> <ul style="list-style-type: none"> • Being aware that lifestyle is a risk factor for dementia • Facing the stigma of dementia within local communities and from service providers 	<ul style="list-style-type: none"> ✓ High levels of awareness amongst staff about healthy living and dementia. ✓ High levels of awareness about the impact for individuals of living with dementia. ✓ Staff aware of techniques and approaches to engaging with a person who has dementia. ✓ Working actively to raise awareness amongst local communities, contractors and other professionals. 	<p>The Dementia Roadmap is a tool to assist primary care staff bringing together high quality information about living well with dementia in a coherent and accessible structure that is easy to use; provides general information about the dementia journey alongside local information about services, support groups and care pathways unique to that locality.⁸</p>
<p>Early stages of dementia:</p> <ul style="list-style-type: none"> • Loss of memory for recent conversations or events • Sometimes confused • Harder to make decisions • Readiness to blame others for mislaid items 	<ul style="list-style-type: none"> ✓ Ability of systems to flag up when someone has dementia. ✓ Awareness particularly amongst front line staff of dementia and its early stages. ✓ Easy access for staff to specialist advice and information, including how to access other services. ✓ Allowing staff sufficient time to explain things more than once to people. ✓ Accessible forms of written information to enable people to refer back as necessary. ✓ Support to making decisions. ✓ Procedures which can be flexed by staff as needed by individuals. ✓ Staff who visit people in their homes to be aware of people's dementia and to have protocols to follow. 	<p>Through their LiveTime service, Riverside have encountered several people living with dementia and accessing little or no support; the service has developed support packages for them, and been successful in helping people receive a diagnosis of dementia via contact with GPs and social services.⁹</p> <p>Notting Hill Housing Trust trained a group of staff from across their services to improve awareness and to act as champions of best practice in dementia care and support, and to be a point of contact for customers, relatives and colleagues.¹⁰</p> <p>Applicants will be mainly older people living with cognitive dysfunction arising from diagnosed dementia, with a short term memory loss, some disorientation, and/or communication difficulties, but to a degree which is assessed as being manageable at the point of entry, allowing them to become settled in their new environment.¹¹</p>

7 Examples from the research report 'Understanding what it means to be a dementia friendly organisation' (Unpublished)

8 <http://www.rcgp.org.uk/clinical-and-research/clinical-news/the-dementia-roadmap-what-is-it-and-why-is-it-needed.aspx>

9 National Housing Federation (2013) Dementia: finding housing solutions

10 Alzheimer's Society (2012) Home Truths

11 Housing LIN (2014) Extra Care at Bletchley Park

The experience for the individual	The service characteristics needed as a response	A selection of practice examples ⁷
<p>Middle stages of dementia:</p> <ul style="list-style-type: none"> • Needing more support with managing day-to-day living • Increasingly forgetful particularly of names • Failure to recognise people or confuse them with others • Confusion between night and day • Putting themselves at risk through forgetfulness 	<ul style="list-style-type: none"> ✓ Front line staff able to recognise signs and respond appropriately. ✓ Specialist advice available to staff, particularly in maintenance, general needs housing and leasehold. ✓ Staff trained to communicate with people with varying levels of confusion. ✓ Systems flag up customers with dementia so information is available to front line staff having contact with them. ✓ Staff understand what assistive technology is available, in what situations it is effective, and how to access it. ✓ Systems which enable a response to alerts from assistive technology and call systems. ✓ Access to assistive technology to promote independent living, such as flood sensors. ✓ Buildings designed to enable independent living. 	<p>Through the use of intuitive lifestyle and environmental sensors, telecare helps manage and mitigate the risks that may arise when a person with dementia is living independently (e.g. falls, wandering, bogus callers and cooking). Environmental sensors can include fall detectors, bed/ chair occupancy sensors, door entry/ exit sensors, gas management sensors, flood sensors. These sensors can be placed in and around the home and are linked to Homecall's 24 hr monitoring and emergency response service.¹²</p> <p>When a flat becomes vacant Bankfield Housing Association has a policy of repainting it, re-flooring the kitchen and bathroom, and replacing any damaged fittings. They now ensure that all toilet/ bathroom doors contrast with adjacent walls & that new flooring matches existing carpets. Threshold strips are removed where possible, in the kitchens some glass fronted cupboards are provided at eye level, making it easy to see the contents without having to remember what goes where.¹³</p>
<p>Later stages of dementia:</p> <ul style="list-style-type: none"> • Gradually more dependent on others for care and support • Pronounced loss of memory • Increasing frailty and reduced mobility • Difficulty in eating or swallowing • Increasingly restless and/ or distressed or aggressive 	<ul style="list-style-type: none"> ✓ Housing staff know how to seek advice and support from specialist organisations ✓ Good partnership working with relevant statutory and third sector agencies. ✓ Where food is provided, for example in extra care housing, menus can be flexed to meet individual needs and preferences. ✓ Menus are designed to be nutritious and balanced. 	<p>The ExtraCare Charitable Trust has developed the Enriched Opportunities Programme (EOP) which focuses on supporting older people with dementia to help them live independently for longer in extra care housing. Research found that EOP participants were 50% less likely to move into a care home (compared to control sites) and experienced a 42% decrease in hospital stays.¹⁴</p>

12 Smith J D and Otter, P Dementia 2014: A North East Perspective (July 2014) <http://www.nr-foundation.org.uk/wp-content/uploads/2014/07/Full-Report.pdf> 138

13 University of Stirling (2013) Improving the design of housing to assist people with dementia

14 Extra care Charitable Trust: The Enriched Opportunities Programme

How dementia friendly Guinness is now

What we did

We tested how dementia friendly Guinness is as an organisation against this picture by interviewing a number of senior managers and carrying out an electronic staff survey. In addition, we carried out a focus group discussion with current customers.

We interviewed 18 senior managers representing different functions and geographical areas, and we also interviewed one external contractor. We asked their views about how dementia friendly they thought Guinness was now, and what we need to change to become more dementia friendly.

The staff survey was completed by 209 members of staff from all functions in the organisation. The questions were broadly the same as for the senior managers, but also asked staff to describe their personal experience of dementia. The majority of respondents had some experience of dementia, mainly from their personal rather than work lives.

The customer focus group was through an existing Guinness Care and Support Customer Group. Five customers attended, all of whom have an existing understanding of what dementia is and all are tenants of The Guinness Partnership; one of the customers is a Dementia Friend Champion.

The focus group was sent a briefing paper in advance which set out the dementia challenge; views on what people with dementia and their carers say are important; staff views on how dementia friendly they think we currently are and ideas on what we could do to become more dementia friendly.

The aim of the focus group was to get an understanding of how dementia friendly participants thought Guinness is now, and to find out what actions they thought we should prioritise to have the greatest impact.

What we found

Awareness of dementia

Senior managers recognised that awareness of dementia varies widely across the organisation and with maintenance contractors. The majority of respondents on the staff survey had personal or work related experience of dementia, and therefore it can be assumed reported a higher level of awareness and interest in the subject than might be expected from those without that experience. There was some concern about how the organisation would translate any awareness into change in the design and delivery of services.

“I think Guinness is trying to make people aware of dementia and is trying to adapt to provide services for this sector now and in the future, however I still think it is a topic a lot of people shy away from.”

Staff reported limited use of existing initiatives to improve awareness of dementia. There is a need for better provision of information. There was no dementia specific training, although parallels were drawn with the training that is provided on safeguarding and general vulnerability.

Proactively supporting people in the early stages of dementia

There was agreement amongst managers that for a variety of reasons, services tended to be reactive rather than proactive. A significant barrier cited was a lack of relevant information about customers in business systems, and the consequent limits to flagging customer needs so as to improve proactive responses.

Although most staff survey respondents agreed that Guinness had a culture of being proactive and supportive, they also prioritised improvements to systems and the need to have a clearer understanding of when normal practice can be changed to meet the needs of an individual with dementia.

“I believe that if people were armed with as much information as possible about the illness then they would be better equipped at dealing with customers in a sensitive manner.”

A strong theme from the research was the need to improve information about the support available to people with dementia both within Guinness and externally. A lack of training meant staff may not necessarily recognise early symptoms for what they were, or know how to respond or advise people appropriately.

A further issue raised was a lack of clarity about what staff are enabled to do in terms of their response when someone was diagnosed with dementia. This lack of clarity applied across all forms of housing including sheltered, leasehold and general needs housing.

“Sheltered schemes often lack flexibility to cater for people as their needs increase, particularly when their mental capacity deteriorates.”

Enabling independent living

There was a clear sense of where there were opportunities to improve how Guinness enabled independent living for people

with dementia, whether this was through improved design in existing and new buildings, maximising the benefits of assistive technology, tailoring the maintenance offer, or proactively targeting support services such as financial inclusion. Staff highlighted the need to look at how maintenance contracts were specified and managed, and this was supported by maintenance contractors.

There is limited use of assistive technology which is relevant to the particular needs of people living with dementia, and a limited knowledge of what Guinness can do in this area for those customers. There are some local initiatives looking at design in planned maintenance and refurbishment, but this work is in its early stages.

“My recent experience has been a positive one, enabling a very elderly resident to remain in her own home, because of my knowledge of assistive technology, knowing who to speak to, and working with social services and an external telecare provider (our hardwired system cannot support add-ons).”

Support as people become more frail

Managers felt that there was not clear guidance as to how standard levels of housing management service could or should be varied to respond to increasing frailty of our customers. Information was not kept about whether customers were carers, and there is no agreed approach to how services or approaches could be flexed specifically to meet carers' needs.

“Having to deal with a complaint from one resident about another resident with dementia without breaking confidentiality was hard.”

Relationships with statutory and voluntary agencies are variable, and staff highlighted the need to develop better working links with these services.

“We can do very little to assist. We can and do contact relatives, friends and the authorities looking for support. Sadly this is not very easy as austerity measures take hold and experts who used to be employed by the authorities dwindle away.”

What staff say needs to be different

There were many individual ideas suggested by senior managers and staff, but with some clear themes:

Staff training and support

Most staff mentioned the need to increase skills and expertise in this area, as well as ensuring access to specialist support and having good, up-to-date information about local services.

Raising awareness

Many suggested the need to raise awareness of dementia not only among staff, but also customers, and the contractors we work with.

Customer intelligence

Many referred to the need to develop a better understanding of who our customers affected by dementia are, their needs and preferences, and whether any changes or new services developed by us have a positive impact for them.

Service offer

There was a strong message that we need to develop a more consistent, clear offer so that our customers and staff know the support we can provide, and what was expected of staff. There was a sense that systems needed to be developed to support the delivery of more

proactive services; some existing services (such as aids and adaptations, assistive technology or financial inclusion) needed to be developed to meet the needs of people with dementia better; and communication and consultation mechanisms needed to be reviewed to ensure they were dementia friendly.

Buildings and the local environment

There has been some work to improve the design of new buildings, and the specifications used for work to existing buildings, but this is in its early stages and needs further development. There needs to be clearer, monitored expectations of contractors and other professionals working in customers' homes.

What customers say we should prioritise

The customer focus group was asked to choose which actions would be the most important for Guinness to develop to have the greatest impact on customers. The highest priority was the strategic review of future replacement of alarm call systems to include requirements of customers living with dementia and the objective to support those customers to live independently, linked to this the use of assistive technology.

The second highest priority was developing a tailored response to maintenance requests which takes account of vulnerable people, recognising that a customer database with relevant information was a prerequisite for this.

Other key areas included: developing a toolkit for staff and customers and more information about services: following up and monitoring actions/information/advice given to customers; dementia friendly design and tailored training for staff.

The implications for Guinness and what we do next

The challenges to becoming dementia friendly

We provide homes, care and support services to 120,000 customers. We employ 3,000 people to do this. Becoming dementia friendly in an organisation the size of Guinness cannot be achieved with superficial initiatives. Systems, processes and training need to support staff to respond flexibly and intelligently to the needs of customers as individuals, including, but not limited to, the particular needs of customers living with dementia.

The costs of making these changes are significant, and the changes must support and improve our customer service, not distract or divert effort and resources ineffectively.

So we developed some key questions against which we could test specific approaches or interventions:

1. How likely is it that specific measures will have an impact for customers living with dementia?
2. How much resource or effort will need to be applied to achieve an impact?
3. Are there measures which are dementia friendly, but which are not dementia specific, so that they also have equivalent benefits for customers who have similar needs?
4. Can we integrate measures to become dementia friendly into

wider change programmes, and do the individual measures join up from the customer's standpoint?

5. Can we test initiatives and evaluate whether and how we could implement them more widely?

What we will do

Based on these tests, our plan to become a dementia friendly organisation is based on the following approach:

- Focus our initial efforts – we will test how we can adapt our service offer for customers living with dementia initially in a pilot area where, based on our customer profile, we can be confident that effective measures will have an impact on a significant number of both our customers, and will enable us to build partnerships with local agencies and community groups to support the development of dementia friendly communities.
- Involve customers and staff in developing our service – both groups have a clear sense of what measures will have a positive impact on becoming more dementia friendly, and we will seek their views on how to adapt our service to be dementia friendly.
- Embed proven, practical measures wherever this is feasible as quickly as practicable, for as many

customers as possible – this will apply to measures which are easier to specify and deliver such as the specification for planned maintenance works, development of new homes, and improving the range of assistive technology that we offer.

- Raise awareness of staff, and improve the advice and support available to them to help customers living with dementia – we have already hit our first target of recruiting 250 Dementia Friends from staff and customers, and have a target to encourage and support 250 more. We will also develop or signpost resources for our staff that gives practical advice and information in relation to dementia. We will have a simple, easy to use, web-based resource for staff which provides them with basic information about how to provide support to customers, and signpost them to relevant services.
- Use our existing change programmes to identify where we can integrate dementia friendly measures into our systems, processes and training programmes, particularly where these will have equivalent benefits for other customers – this reduces the risk that we distort our improvement and change programmes, and allows us to test whether we are delivering the intended outcomes.

**Great service,
great homes and
a great place to work**

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