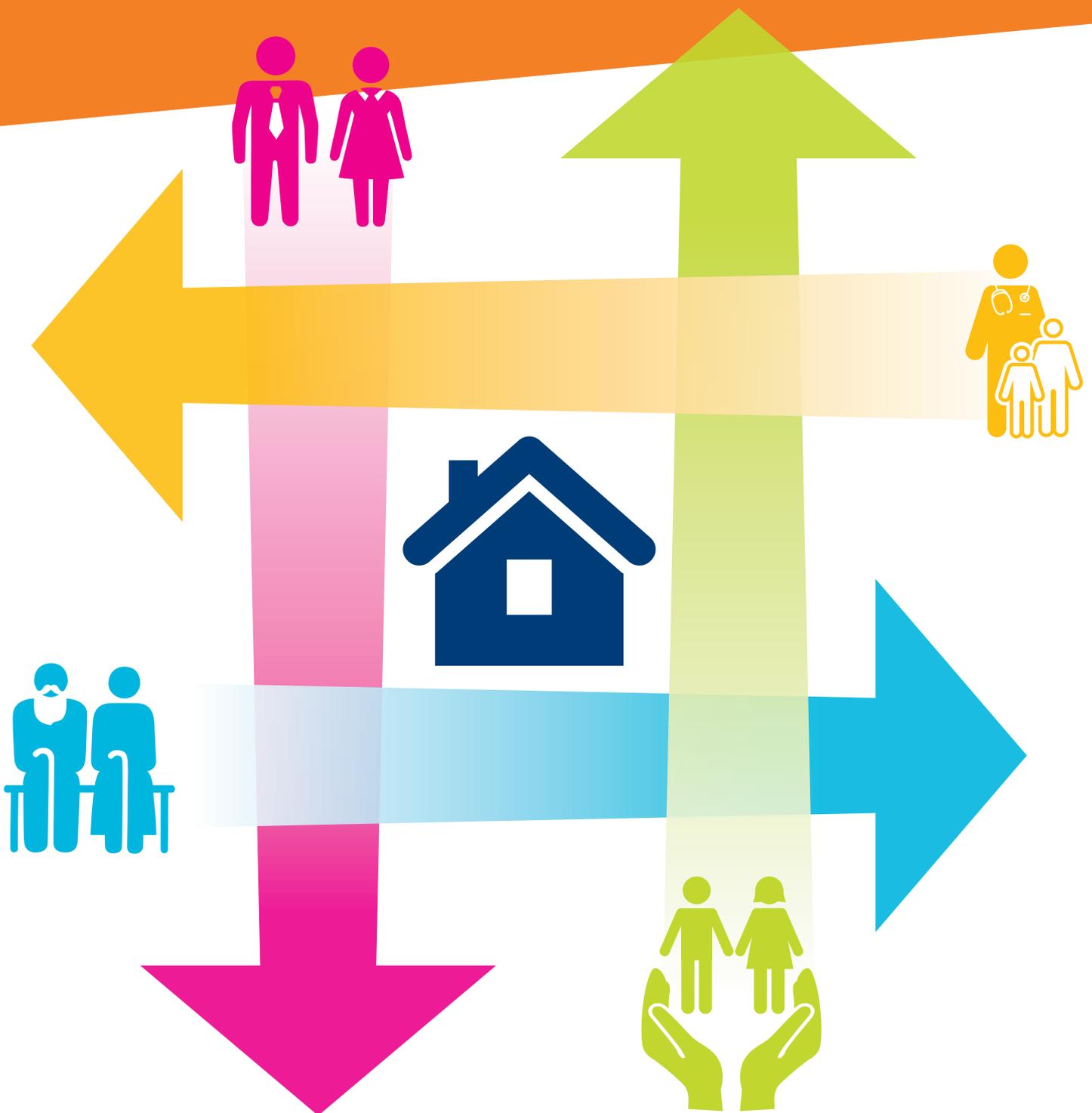


# Transforming care pathways for people with dementia

Linking housing, health and social care



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# Introduction

**At a time of budgetary restrictions and a rapidly ageing population, the need to find radically new ways of supporting people to live well in later life is becoming urgent. There have been significant policy commitments to move services from hospitals into the community over recent decades, most recently through the NHS Five Year Forward View. However, this has yet to translate into a major shift in service provision or funding allocations. In fact, while the NHS – and especially acute hospital services – have received major cash injections, spending on local authority social care has fallen by 26% in the last five years<sup>1</sup>.**

This report builds on the National Housing Federation's 2013 publication *Dementia – finding housing solutions*<sup>2</sup> and subsequent work that has been carried out through our strategic partnership work with the Department of Health. The National Housing Federation's subsequent report *Prescription for Success* identified a number of areas for action that will help to transform dementia care pathways, to better support people living with dementia and their families. Housing associations are ideally placed to help health and social care commissioners deliver this change; promoting more integrated service pathways, applying the best evidence to practice, and co-designing support packages with individuals to ensure better health outcomes.

This report is aimed at health and social care commissioners and service providers. It sets out to encourage closer working with housing providers at a local level, to design more robust and coordinated pathways of support for the increasing number of families who will be living with dementia over the next few decades. Case studies throughout this report highlight innovative examples of the contribution housing can make to helping people live well with dementia. Our six helpful steps outline a potential route to achieving the transformation that is needed.

**'Housing associations are ideally placed to help health and social care commissioners transform dementia care pathways to ensure better health outcomes.'**

<sup>1</sup> ADASS, Distinctive, Valued, Personal. Why social care matters - the next five years, 2015.

<sup>2</sup> National Housing Federation, *Dementia – finding housing solutions*, 2013.

# Dementia in context

The need to invest in research and improve the coordination of services and support for people with dementia is high on global and national policy agendas. In the recently refreshed 'Prime Minister's Challenge on Dementia'<sup>3</sup>, David Cameron set out the following ambition for transforming dementia care in England over the next five years.

'We are working harder than ever to improve dementia care, to make England more understanding of dementia, to find out more about the condition and to find new treatments which delay onset, slow progression or even cure dementia.'

The predicted rise in the number of older people is well documented. We know that as the proportion of the population living to late old age grows, the number of people living with at least one long-term health condition will also increase. This includes people having to adjust to life with dementia<sup>4</sup>.

Increased levels of physical and mental frailty among people aged over 85, the so-called 'oldest old', will significantly increase demand for age-appropriate housing, care and support in future<sup>5</sup>. With the policy emphasis firmly on community provision rather than institutional care, housing, health and social care commissioners and service providers can expect to see a significant rise in the number of households needing help to live at home. While additional funding for research into drug treatments and potential cures for dementia is welcome, there is a danger that funding for care and support is moving in the opposite direction.



There are **800,000** people living with dementia in the UK today (accounting for 1 in 4 of the population aged 65 and over, with prevalence increasing with age).



The number of people living with dementia is expected to double in next 30 years.



The predicted cost is **£26.3bn** in health, social care and informal care.

<sup>3</sup> Department of Health, Prime Minister's challenge on dementia 2020, 2015.  
<sup>4</sup> Dementia UK and Alzheimer's Society, 2014

Access to publicly funded care in England is highly restricted and subject to stringent eligibility criteria and means testing. Despite the historically unprecedented ageing of the population, fewer households are receiving local authority-funded support for home-based or 'domiciliary care' because of the severe pressure on public finances.

The Care Act 2014 set the new nationwide eligibility criteria at the equivalent of 'critical' or 'substantial' need, based on the previous Fair Access to Care Services (FACS) criteria. Previously 90% of English councils only provided services for people with critical or substantial need<sup>5</sup>, but research from the Personal Social Services Research Unit (PSSRU) shows around 436,000 older and disabled people who would have got care in 2005/6 are now no longer entitled to it<sup>6</sup>. At the same time the Department for Work and Pensions (DWP) estimates that one in six (10.7 million) people in the UK can currently expect inadequate retirement incomes<sup>7</sup> and successive public opinion surveys show that few households have made financial provision to pay for long-term care<sup>8,9</sup>.

Research shows that the availability of informal or family carers of working age is likely to decrease<sup>10</sup>. This means that the responsibility for providing intensive care for people living with dementia and other long-term health conditions will increasingly fall on older partners and spouses. Investing in workforce recruitment and development is therefore crucial, if people are to receive the help they need to live well at home with a good quality of life<sup>11</sup>. There is an urgent need for investment in services to support families, friends and community volunteers who will continue to provide the majority of care and support.

Leading policy think tanks such as the King's Fund, and the Association of Directors of Adult Social Care, have warned that the current situation is unsustainable, and that new models of cost-effective and coordinated or 'integrated care' are required<sup>1,8</sup>. Housing has a crucial contribution to make in this agenda.

The landmark *Memorandum of Understanding*, aimed at bringing housing, health and social care together, recognised this when it was published in December 2014<sup>12</sup>. However, high-level policy statements cannot transform services on the ground. This requires close collaboration, a shared understanding of needs, and a willingness to share risks and resources, within and between different sectors.

This report builds on that commitment to joint working, providing commissioners and potential service partners with robust examples of how housing associations can help transform care pathways for people with dementia, using emerging innovation and best practice from across the country.

**'Investing in workforce recruitment and development is crucial if people are to receive the help they need to live well at home with a good quality of life.'**

<sup>5</sup> Jagger, C., et al., Capability and dependency in the Newcastle 85+ cohort study. Projections of future care needs. BMC Geriatrics, 2011.

<sup>6</sup> PSSRU (2013), Changes in the patterns of social care provision in England, 2005/6 to 2012/13.

<sup>7</sup> Calculation based on Office for National Statistics (ONS) mid 2013 population estimates for the UK (total population = 64.1 million).

<sup>8</sup> King's Fund, A new settlement for health and social care - Interim report, 2014.

<sup>9</sup> National Housing Federation, Can our homes pay for the care we need in older age? Asset wealth and an ageing population, 2015.

<sup>10</sup> Wittenberg, R., et al., Care for older people - projected expenditure to 2022 on social care and continuing healthcare for England's older population. Nuffield Trust, London School of Economics and PSSRU, 2012.

<sup>11</sup> Garwood, S., Making a start. Dementia - skilling the general needs housing workforce. The Housing and Dementia Working Group, 2014.

<sup>12</sup> HM Government, A Memorandum of Understanding to support joint action on improving health through the home, 2014.

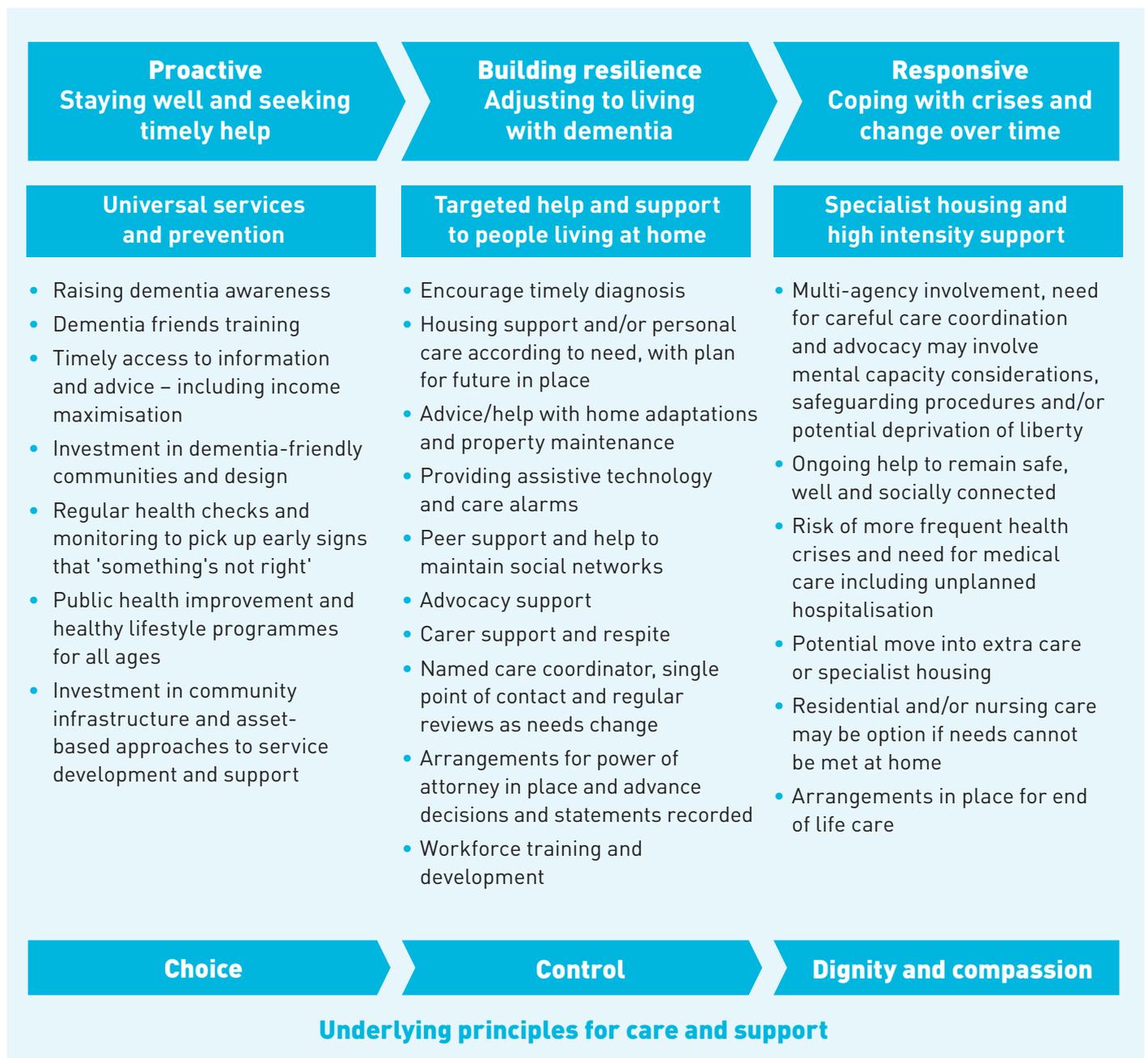
# Time to think differently

**Until very recently, dementia was largely seen as a condition of old age, requiring specialist treatment in residential settings.**

While there is currently no medical cure, we have developed a greater understanding of the different types of dementia, the problems that it causes people living with it and their carers, and

how to develop more effective models of support. There are three interconnected tiers or types of intervention that contribute to an effective system of care and support. If properly planned and coordinated they will support people at different stages of their life-course, including their journey and contacts with services before and after a diagnosis of dementia.

**Figure 1: Elements of a connected care pathway**



### Some problems with pathways

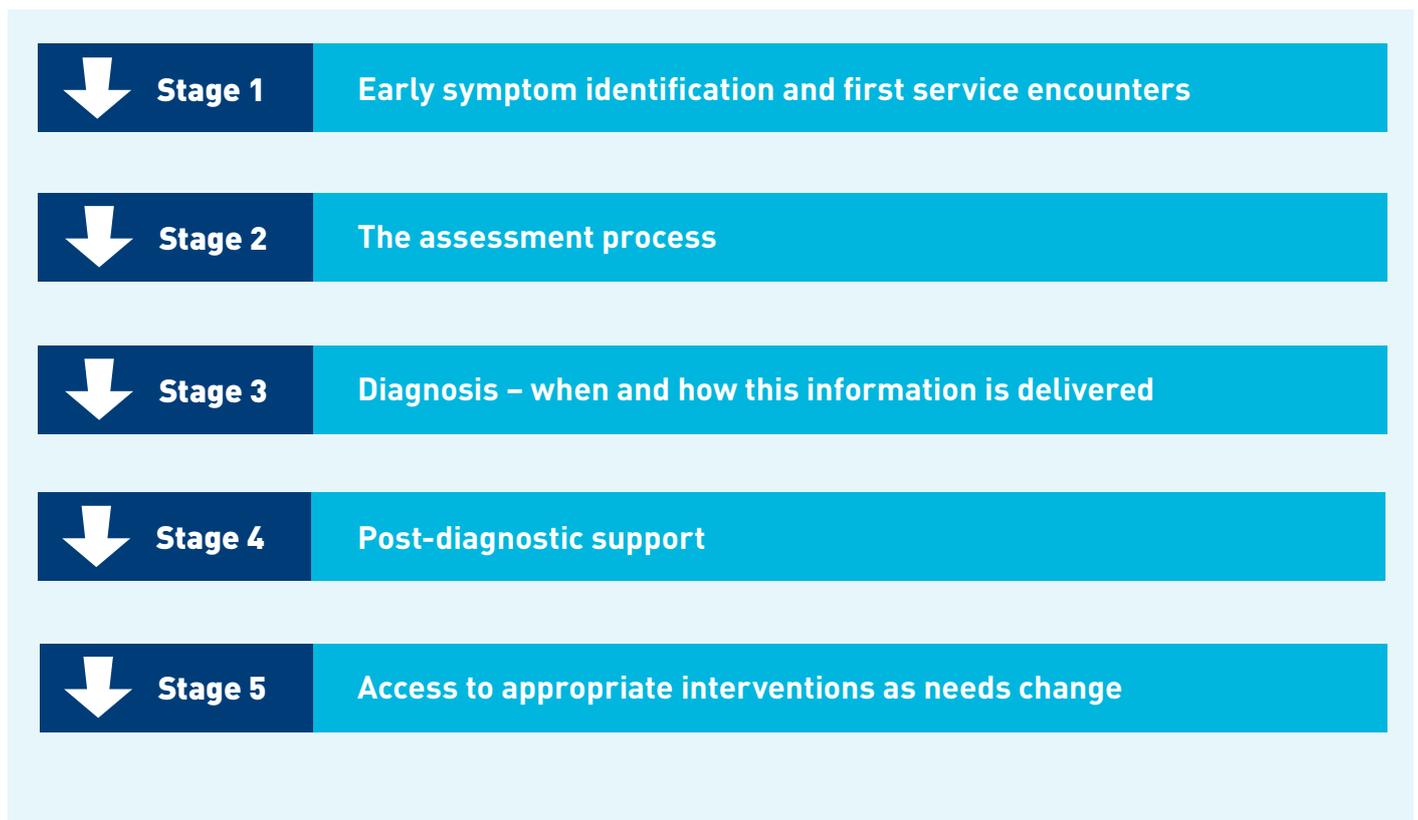
The idea of 'care pathways' as an agreed set of protocols or steps that lead logically from diagnosis through a set of planned service interventions, investigations and specialist referrals has grown in popularity within health and social care over the last decade<sup>13</sup>. However, it is highly likely that most people diagnosed with dementia will be living with one or more long-term conditions as well as coping with what might be seen as 'normal' changes in health and mobility associated with ageing.

As a result, dementia care pathways cannot be viewed in isolation from older people's strategies and specialist pathways for managing other long-term conditions, such as diabetes, arthritis,

sensory-loss, continence-promotion, falls-prevention, and pain management. In fact, someone diagnosed with dementia is likely to be subject to multiple 'health and social care pathways,' and it is the lack of coordination between them that often leads to problems.

Research for this report has shown that not all local authorities have separate dementia care strategies. In some areas dementia is included within mental health strategies, while in others it forms part of a general older person's strategy to inform commissioning. In their review of dementia care pathways<sup>13</sup>, Samsi and Manthorpe identify five key stages that should be reflected in workforce development strategies, and plans for coordinated service models.

**Figure 2: Dementia care pathways – key stages**



<sup>13</sup> Samsi, K. and J. Manthorpe, Care pathways for people with dementia - current perspectives. Clinical Interventions in Ageing, 2014.

Taking a person and family-centred approach helps to counter 'systemised ways' of organising services that are often designed with the needs of organisations and professionals in mind, rather than those of the people needing support. The unique needs and circumstances of every individual – as well as those of their immediate support network – should be fully understood prior to any assessment or diagnosis. This will ensure a more holistic response to the changing needs that a diagnosis of dementia brings, with the assets and resources available within the local community factored in to any planned system of care and support interventions.

### **Delivering person and family-centred care**

There is widespread agreement that people living with dementia, and their families, should be supported to achieve the best quality of life that is possible as their condition progresses<sup>3,14,15</sup>. The challenge is to translate these policy ambitions into everyday practice, transferring greater choice and control to individuals to help them shape the care and support they receive.

This means making information widely available in formats that reflect different communication needs, and making sure that everyone has easy access to specialist advice and support. There is now a greater range of home-based support interventions – including technological innovations and assistive technology – that aims to reduce the risk of crisis admissions to hospital and residential care.

In theory, it should be possible to match services and support to changing needs and priorities. We know that providing safe, warm, accessible and affordable housing will support people to live at home to the end of their lives. Thinking differently and joint working between housing, health and social care, produces positive results a local level. By learning from these innovations and examples of promising practice, we might begin to transform care pathways for people with dementia.



### **Key message**

A radical shift towards a personalised and coordinated model of care and support is required, reflecting the unique needs, circumstances and priorities of the person living with dementia. The important contribution made by families, friends and wider community support networks needs to be recognised.

<sup>14</sup> D'Alton, S., et al., Adapting to dementia in society: A challenge for our lifetimes and a charge for public health. *Journal of Alzheimer's Disease*, 2014.

<sup>15</sup> All-Party Parliamentary Group on dementia, *Building on the National Dementia Strategy – change, progress, priorities*, 2014.

# 1 Investing in prevention

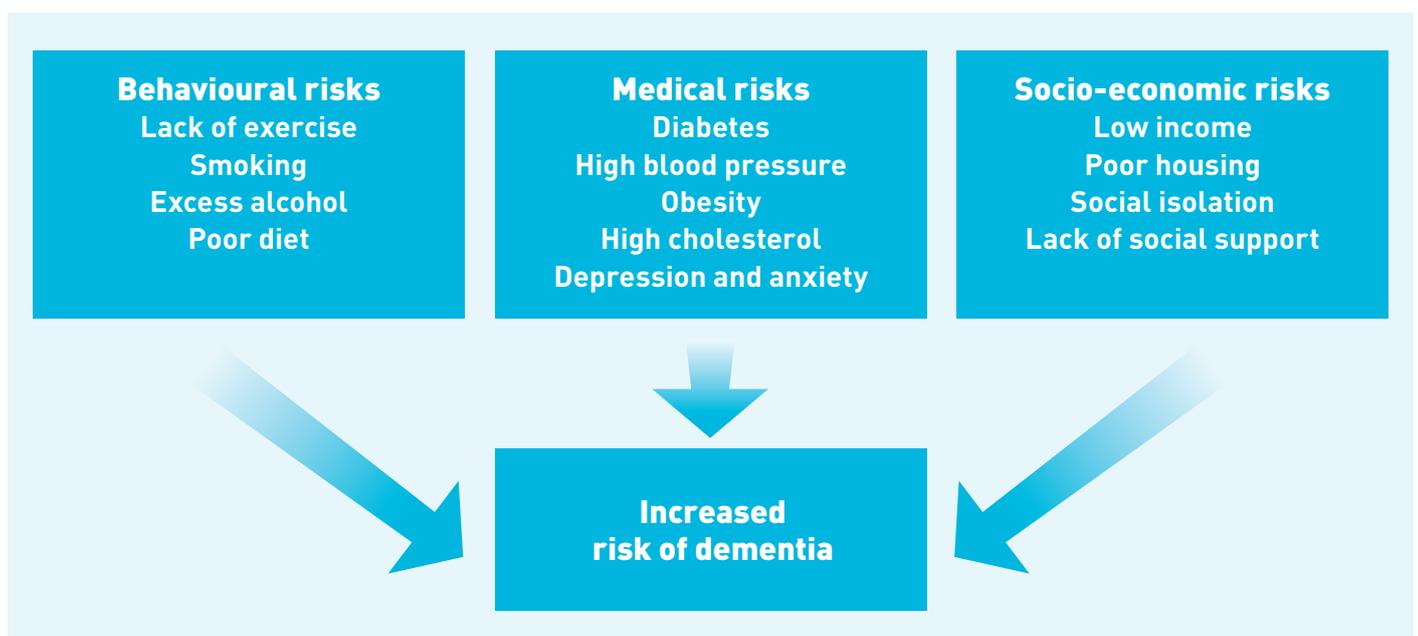
## Promoting good mental health in later life

The Care Act 2014 and the NHS Five Year Forward View<sup>16</sup> set out a radical new approach, emphasising the need to invest in preventative and coordinated care to reduce the demand for crisis services. Health agencies and local authorities have a new duty to promote wellbeing across their local area, as well as targeting individuals that use their services. The emphasis on 'universal services,' aimed at improving the health and wellbeing of the wider population, is reflected in public health strategies, general policy for older people, and policies specifically relating to mental health and dementia. Added to this, there is increasing recognition that promoting health and wellbeing across the life course means giving equal attention to mental and physical health<sup>16,17</sup>.

There is a growing body of research to evidence that preventative health measures can help reduce the risk of cognitive decline in later life<sup>18,19</sup>. Prevention includes focusing on the causes of poor mental health and a lower quality of life, including problems resulting from depression, dementia, and social isolation<sup>19,20</sup>.

Housing associations are ideally placed to help with this. They have a long track record of work on the social determinants of health through their community investment programmes and health and wellbeing initiatives. This places them in a strong position to support health and local authorities in reducing the prevalence of dementia through universal information services and public health improvement programmes.

**Figure 3: Factors that increase the risk of dementia**



<sup>16</sup> NHS England, Five Year Forward View. 2014.

<sup>17</sup> Public Health England, From evidence into action – opportunities to protect and improve the nation's health, 2014.

<sup>18</sup> Mangialasche, F., et al., Dementia prevention – current epidemiological evidence and future perspective. Alzheimer's Research and Therapy, 2012.

<sup>19</sup> Public Health England and UK Health Forum, Promoting brain health – developing a prevention agenda linking dementia and non-communicable diseases, 2014.

<sup>20</sup> International Longevity Centre UK, Preventing dementia - a provocation, 2014.

A coordinated national and local programme is needed to reduce the incidence of poor mental health, including dementia, through:

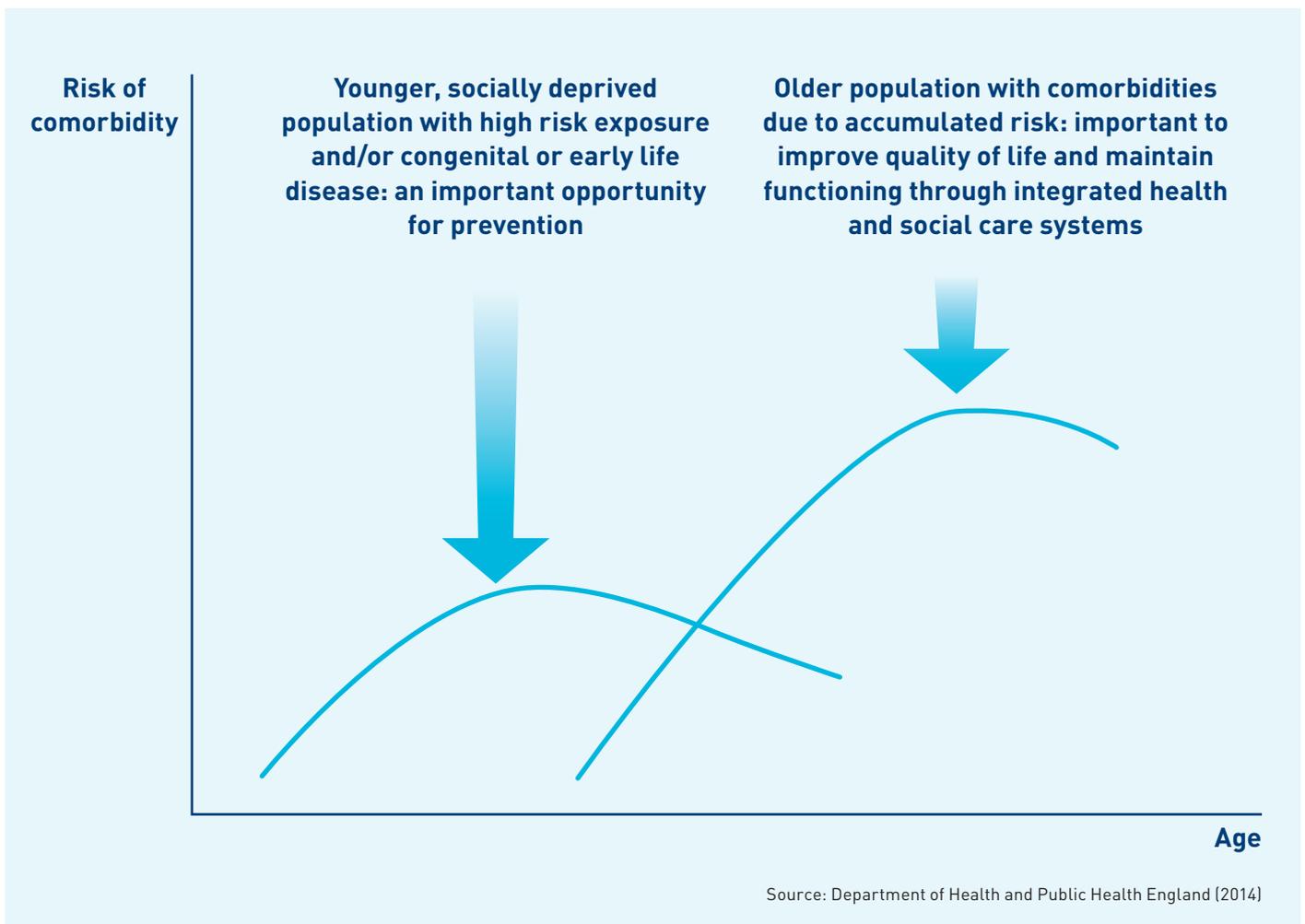
- Public awareness and information campaigns
- Public health programmes to improve individual lifestyle choices and behaviour
- Building strong community networks to offer social support and tackle social isolation
- Actions to tackle poverty and the structural causes of health inequality; including investment in decent homes and neighbourhoods, income maximisation and timely access to services.

Alongside these measures, there is a need to change the way other health conditions are monitored and managed across the life course, and not just in old age. This includes giving individuals more power and control to manage their long-term health.

### Tackling inequality

Recent work by the Department of Health and Public Health England<sup>21</sup> highlights a need for targeted interventions to improve the health of two high risk population groups as outlined below.

**Figure 4: Population groups at risk**



<sup>21</sup> Amina, A.,-S., Co-Morbidities Framework – a framework of principles for system-wide action. Department of Health, Public Health England, NHS England, 2014.

People with learning disabilities and complex support needs are also at a higher risk of developing poor mental health in later life<sup>15, 22</sup>.

Housing associations that offer supported accommodation and specialist community-based support recognise this. They are actively supporting people of all ages to adopt healthier lifestyles, improving overall health and wellbeing and reducing pressure on NHS services further downstream as the following example shows.

## Case study

### Isos Housing – HAPs and WRAPs

Isos Housing offers a range of support options to improve the health and wellbeing of people living with mental health problems. Their person-centred flexible approach incorporates a wide range of tools to suit individual needs, enabling service users to plan their support journey and their longer term goals in a holistic way.

Tools such as the Wellness Recovery Action Plan (WRAP) and the Health Action Plan (HAP) are used alongside support plans to equip service users with relevant coping strategies and useful prompts which they can use during their support pathway and – importantly – can continue to use when they move on to independence. Health Action Plans encourage service users to live a healthy lifestyle, paying particular attention to healthy eating, exercise, smoking cessation and weight control, as well as promoting the importance of regular health checks. Wellness Recovery Action Plans help service users recognise the triggers associated with a decline in their mental health, enabling early crisis intervention and reducing the number of emergency hospital admissions. Currently ISOS has 300 service users with HAPs and WRAPs in place.

Throughout the period of support Isos will also facilitate activities, events, training and employment support, to promote the first steps towards inclusion and community involvement, and capacity building, to enable individuals to better manage their mental health longer term.

People from different communities have varying needs as they age, and housing associations are already aware of the specific difficulties communities might face. The number of people with dementia from black, Asian and minority ethnic (BAME) groups in the UK is expected to increase seven-fold in 40 years. This compares to just over a two-fold increase in the number of people with dementia across the whole UK population over the same time period<sup>23</sup>. Partnering with housing providers that work within these communities will improve access to services and help to address health inequality.



## Key message

Housing associations are well-placed to work with public health teams to publicise healthy lifestyle and dementia awareness campaigns. They can use their customer communication channels, community health projects and assertive outreach projects to reach people who are less likely to engage with formal public health agencies. They can also help promote mental health by working to tackle social inequalities and through providing targeted support to people at greater risk of poor health in later life.

<sup>22</sup> Holland, T. Ageing and its consequences for people with Down's Syndrome, 2006.

<sup>23</sup> All-Party Parliamentary Group on dementia, Dementia does not discriminate, July 2013.

## 2 Recognition and diagnosis

### The case for timely diagnosis

Public opinion surveys reveal considerable anxiety and social stigma about being diagnosed with dementia. Currently just over half (around 59%) of people living with dementia receive a formal diagnosis, with rates varying considerably across the country and between different socio-demographic groups<sup>3</sup>. In 2012, the Government set a target to increase the overall diagnosis rate to 66% and GPs are monitored on their success in meeting this aim<sup>3</sup>.

Promoting awareness of dementia and encouraging people to seek medical help early is important, as timely diagnosis gives people better access to information and support, including appropriate medication. It also helps individuals and their families plan for the future; sorting out finances, making housing-related decisions, thinking about issues such as power of attorney, discussing personal preferences and priorities, and planning for end of life care.

### How housing can help

Housing data systems can be used to support early intervention programmes. Housing associations are experienced in acting swiftly when frontline intelligence shows that 'something's not right' and taking a 'case-finding' approach can build on this.

Housing staff can often also help people diagnosed with dementia to access reliable information and home adaptations, as well as helping with practical issues such as managing household bills – all of which supports their continued independence.

The following case study shows how one association in Sunderland is working with a local council, a GP practice and its Clinical Commissioning Group, to pilot a new initiative for early interventions when physical health and or age-related memory loss becomes a cause for concern.

### Case study

#### Gentoo – Healthwise system

Gentoo, a Sunderland-based housing association, is piloting a new software package it has developed called 'Healthwise'. With funding support from the North East Dementia Alliance, the system records concerns, monitoring individuals who might be at risk of losing their independence or experiencing age-related memory loss.

Gentoo conservatively estimates that 750 people are living with dementia in its properties – a figure set to increase to around 1,000 over the next 15 years. The Healthwise system pulls intelligence, gained by frontline staff through contact with customers, into the current housing management system. It can then proactively flag up that 'something's not right'. For example, if maintenance staff are regularly changing the locks on a property due to loss of keys, or if an older person suddenly falls into rent arrears, it might imply that someone is experiencing problems with their memory. Frontline staff may notice other indicators of possible health problems, including property neglect, confusion, memory loss, or social withdrawal and isolation. By recording their concerns on the Healthwise system, a referral to the in-house 'Wellbeing team' is triggered. The Wellbeing team will contact the individual concerned and arrange a home visit where appropriate. The team then completes a holistic needs assessment and arranges appropriate follow-up action if necessary.

**To support the process, all frontline staff have received dementia awareness training to help them identify problems before they become a crisis. Members of the Wellbeing Team have also received training in memory screening and dementia awareness from a local GP practice, with support from the Clinical Commissioning Group. If there is cause for concern, Gentoo will – with consent – refer people to their GP and or local Memory Service for further assessment. The Wellbeing Service is jointly funded by Gentoo and Sunderland Adult Services, and offers help and support across housing tenures through this joint funding arrangement.**

**By making the Healthwise system available to nearly everyone that a resident might encounter, it is less likely that problems will go unreported, and repetitive and confusing visits that can be distressing are avoided. The system promotes early intervention and care coordination and enables Gentoo to effectively use in-house interventions and liaise with the appropriate agencies, ensuring the best wellbeing for the individual and their carers. It also supports the safeguarding of potentially vulnerable adults.**

Most housing associations also have the ability to generate detailed demographic profiling data. This presents opportunities for joint working with health and local authority analysts, sharing geo-demographic profile information to better inform joint strategic needs assessments and commissioning plans. This brings the potential to align local housing development plans with commissioning strategies for older people – especially useful in areas of socio-economic hardship, whose populations might need targeted help and investment to address inequalities in health and access to services and support.

### **Using housing data and intelligence**

Almost a third of housing association residents are aged 65 and over and this proportion is growing rapidly<sup>9</sup>. For some associations, this figure is much higher. Given the rapid ageing of their resident profile, it is no wonder that housing associations are

committed to improving the health and wellbeing of their older customers. Using customer profile data to better understand the needs of their older residents has helped many associations ‘age proof’ their strategic development plans and identify potentially vulnerable households. As a result, they are in a better position to offer information and more timely support interventions. These might include advice on different types of housing options, help to organise home adaptations, regular monitoring visits, and help to access other services. Riverside Housing Association’s ‘LiveTime’ service is a good example.

### **Case study**

#### **Riverside Housing Association – LiveTime service**

Riverside works primarily in the North West of England. By 2020, over half of its residents will be aged 55 or over. In 2011, Riverside surveyed its older residents and found that a significant number were anxious and concerned about developing dementia. In response, it developed its new ‘LiveTime’ service, which provides early intervention, timely information and ongoing support to its older customers; with staff encouraging customers to seek medical assistance if they are concerned about any symptoms themselves.

Recognising that only a minority of older people live in sheltered or extra care housing, the service supports older people living in general needs accommodation by providing face-to-face health checks and organising activities to help combat social isolation. With a team of five people and a project manager, the service supports 6,000 older people living in Merseyside, the Midlands, and Cumbria. It offers them general housing support and signposting to resources, such as home adaptation and improvement agencies, as well as help with income maximisation and other financial matters. The LiveTime team has received dementia awareness training and understands the social, physical and accommodation needs of customers with the condition. The team has worked in partnership with the ‘Life Story Network’ to increase dementia awareness for both Riverside customers and staff, which has been very successful.

Receiving a medical diagnosis of memory problems should be the trigger that links people to local referral systems or 'dementia care pathways'. However, as already discussed, the extent to which these include consideration of housing needs or involve housing providers varies across the country. Failure to connect with housing associations is a missed opportunity to provide a more person-centred and flexible range of support as they offer a workforce with more frequent 'doorstep' contact with older people than many statutory agencies, including GPs.

Housing associations are also developing a range of community support services that improve access to information, help and support, as well as opportunities to maintain important social links and relationships. This includes harnessing local volunteers and building new peer support mechanisms to help people adjust to living with dementia.

## Case study

### Housing & Care 21 – Self-help and peer support

Peer support in dementia care helps with early diagnosis and can provide support in the early stages of the condition. By forming groups of older people, the peer support approach also helps tackle key health and wellbeing issues such as loneliness.

Housing & Care 21 has been putting this approach into practice with great effect. An evaluation by the Mental Health Foundation (MHF) and Joseph Rowntree Foundation confirmed that its groups have a positive impact on participants' wellbeing, offering social support and practical coping strategies. It found that participants improved in their communication abilities, and in managing their memory and their lives in general. While there was some deterioration in the independent living skills of participants over time, the high level of physical frailty and impairment among group members meant they were unlikely to improve in this area.

The evaluation also showed the need for peer support groups to become more embedded within Housing & Care 21's schemes, with dedicated staff time and resources directed towards encouraging meaningful activities. It found that these groups were more sustainable over time if volunteers were actively involved in their facilitation.

The MHF has secured Big Lottery funding to run the programme for a further three years. Working with Housing & Care 21's residents, the remit of the group is being extended to focus on people who are socially isolated or lonely.

## Supporting carers

Promoting dementia awareness training for staff working in both general needs and specialist housing (including maintenance staff and contractors) makes good business sense for housing associations<sup>11</sup>. Through extending training we can improve information sharing with families, friends and neighbours, helping to ensure they are better able to access services, appropriate help and information. By tackling stigma and raising awareness about dementia, people are better equipped to deal with some of the challenges and behavioural changes that someone with the condition might experience as it progresses.

Housing associations are well placed to provide vital support to family carers and progress the Government's targets for three million more volunteer 'Dementia Friends' to be recruited and trained by 2020<sup>3</sup>.

## Case study

### Gedling Homes – supporting carers in Nottinghamshire

The health and care commissioning landscape has changed in Nottinghamshire as a result of NHS and social care reforms. An informal network of health and care delivery agencies has evolved to support the County Council and the Health and Wellbeing Board. District and Borough Councils have set up Health and Wellbeing Delivery Groups that help to implement countywide strategies at the local level, making their case for funding investment to the Clinical Commissioning Group (CCG).

In Gedling there is a particularly proactive delivery group, led by the District Council. It includes a representative from Gedling Homes (part of the New Charter Group) and members of the Nottinghamshire North and East CCG. The CCG has provided Gedling Homes with £50,000 in funding to support 250 carers, both young and old, living in Gedling properties. By supporting carers, the CCG is also supporting health and care services, through easing the burden of crisis admissions and early entry into long-term care.

Support varies according to need but is broadly split into four categories: Services, physical activity, social inclusion, and training. Outcomes that Gedling Homes are aiming to achieve include: reductions in self-reported depression levels, increased mobility, reduced stress, reduction in GP and hospital visits, increased awareness of the available support services, increased physical activity levels, maximised income, and increased skills and employability.

## 3 Helping people to live well with dementia

### Community-based support

Building on their success in providing high quality services and support to existing customers, housing associations are increasingly in a position to expand their offer to older people and their families across different housing tenures. This includes people who own their own homes and those living in the private rented sector, as well as those purchasing services with personal budgets.

The ability to transfer services and learning in this way makes housing associations important partners for health agencies and local authorities. They can collaborate with other service providers, such as domiciliary care agencies and voluntary and community groups, working with local branches of Age UK and the Alzheimer's Society for example. This means they can take a joint approach to transforming local services and support for people living with dementia and their carers regardless of the housing situation. Housing associations can act as prime contractors, or work in partnership as part of a longer supply chain or network of service delivery agencies.

Operating as regulated social businesses with strong governance and risk management procedures in place, housing associations can use their experience, expertise, assets and resources to form strategic partnerships, and develop more collaborative forms of service provision. Reflecting the shift to more personalised commissioning models, housing support providers can work with individuals (including people with complex needs) to design flexible packages of support that can be easily adapted as individual needs change over time. These joined up service models are also easier to access and have the potential to bring economies of scale, as the following case study describes.

### Case study

#### Coast & Country – One-stop-shop

In Redcar and Cleveland, Coast & Country Housing has launched a 'one-stop-shop' single point of access service to help people live independently in their own homes. Coast & Country's HomeCall division already provides Telecare support, where an alarm alerts a 24-hour contact centre if there are signs of potential problems or emergencies. By forming a partnership with a local homecare provider (Heritage Healthcare) the HomeCall Independent Living service has expanded the service to offer flexible and tailored support to people in their own homes, across all housing tenures, offering:

- Assistive technology services, including a range of alarms and sensors
- Handyman and property maintenance services, ranging from odd jobs to more complex tasks
- Personal care, including dressing, bathing and help getting in and out of bed
- Practical support, including housework and preparing meals
- Social support, companionship or help getting out and about

Providing joined-up, integrated support means that people receive help to alter the fabric of their homes and no longer have to worry about keeping their gardens maintained or getting niggling property repairs carried out. A selection of 'intelligent' Telecare sensors can be fitted around the home, in locations identified in a formal assessment, to monitor health, safety and security, and help with fall prevention.

Through the HomeCall service, Coast & Country responded to 1,231 falls in 2014/15. 86% of these were dealt with simply by its HomeCall Independent Living Advisor attending the emergency. Without the HomeCall service, the North East Ambulance Service (NEAS) would have been required to respond to an additional 1,064 emergency calls across the Tees Valley in 2014/15, costing it an extra £354,312.

While currently focused on the Redcar and Cleveland area, the ultimate aim is to expand the service across Teesside, North Yorkshire and the North East.

Another model of integration is to use existing property owned by housing associations to provide multi-use community service hubs. Located in the heart of local neighbourhoods, these bring a range of organisations and service providers together on a single site. Notting Hill Housing Trust has used this approach to create a series of 'dementia hubs' across London.

## Case study

### Notting Hill Housing Trust – Dementia Hubs

Notting Hill Housing Trust is committed to making full use of its extra care facilities to provide coordinated care at a local level. The Penfold Community Hub provides access to a wide range of services and information and receives funding from the City of Westminster and Central London Clinical Commissioning Group. It is available to anyone over 50 who lives in Westminster, with an emphasis on those who are isolated, vulnerable or frail.

The hub provides the following:

- Regular information sessions, provided by staff from the Dementia Centre, at different locations in the community. These are open to all older people and carers and focus on issues or concerns around dementia.
- An appropriate programme of activities suitable to meet their needs, either provided directly by the Hub or by other local agencies.
- Referrals of individuals and family members to the Dementia Adviser when there are concerns about possible symptoms.
- A Dementia Café to promote the Hub to people with dementia and their carers, including sessions at Lord's Cricket Ground and Westbourne Park.

Learning from the hubs is informing plans to develop local dementia-friendly communities. Notting Hill Housing's model includes a shared strategic approach across multiple strands of activity aimed at improving dementia care. These include: extra care services, day services, community service hubs, sheltered housing, housing support services, and estate management.

### Added economic benefits

In its recent report on the state of social care, the Association of Directors of Adult Social Services (ADASS) argues that locally developed care enterprises bring added social value and economic benefits to local areas<sup>1</sup>. It found that they create new training and employment opportunities for local residents, harness the talents of local volunteers and community groups, and make better use of community assets and resources. When care enterprises are delivered in partnership with housing associations, they generate added investment for local affordable homes, as well as better neighbourhoods and improved local services.

## 4 Meeting changing needs

### The right help at the right time

Research with people aged over 85 living in their own homes has shown that shopping and heavy housework are the type of domestic activities where most help is required in later life<sup>5</sup>. Bending down to cut toenails is one of the personal care tasks that causes the most difficulty, and these everyday tasks can be even harder for someone living with dementia. Maintaining independence also becomes more of a challenge if mobility declines. Studies show that around half of women aged over 85 experience some difficulty with walking more than 400 yards, and 40% of men<sup>5</sup>. One in three people aged over 65 fall each year, and half of all those aged over 80. People with dementia are at increased risk of falls<sup>24</sup>. Impaired vision, loss of hearing, problems with balance and decreased awareness of environmental hazards that may accompany dementia, can also contribute to this<sup>25</sup>.

Housing associations have developed a range of services that help people in advanced older age live independently. Through their community support and property maintenance services, most housing associations can fit key safes, help with repairs, adaptations and redecoration, as well as taking care of gardening, carrying out small repairs and minor adaptations. All of these things can be important in supporting independence and can also help people maintain their connections to their neighbourhood and wider community.

### Environmental design and adaptations

There is greater awareness within the sector of the environmental adaptations that help someone with dementia maintain their independence. The top ten housing adaptations have been outlined by the Dementia Services Development Centre<sup>26</sup>.

<sup>24</sup> NHS Confederation, Ambulance Service Network, Community Health Services Forum, Falls prevention - new approaches to integrated falls prevention services, 2012.

<sup>25</sup> Social Care Institute for Excellence, Living with dementia/sensory loss.

<sup>26</sup> Dementia Services Development Centre.

### Top ten housing adaptations for people with dementia

1. Double the usual levels of lighting in the home. 
2. Pay attention to acoustics and reduce noise pollution. 
3. Ensure there is good signage mounted low enough for poor eyesight. 
4. Place illuminated clocks in each room indicating whether it is am or pm. 
5. Ensure that people can see important rooms such as the toilet, that furniture and fittings give strong clues to the purpose of the room and that there are clear signs. 
6. Use contrast of colour or tone to make switches and objects easily visible. 
7. Ensure that kitchens and bathrooms are easy to understand. Avoid new designs for things such as taps and kettles. 
8. Use contrast of tone (rather than colour) to differentiate between walls, skirting boards and floors. Ensure that floors are of a consistent tone. 
9. Use objects or pictures rather than colours to distinguish between different parts of the building. 
10. All doors should be visible on entering the dwelling. Cupboards should be glass fronted or open. 

By adapting homes in response to changing needs – installing assistive technology for example – housing associations can help prevent crises for people with dementia. A range of sensors can be fitted to make the home environment safer. These might include: flood detectors, gas shut-off systems, falls and movement detectors, domestic sprinklers, and medication alerts<sup>27</sup>. Assistive technology can help relieve carer stress and isolation, with family members able to feel more confident about leaving the house, knowing that they will be alerted if someone with dementia leaves the home, the bath overflows, or the cooker is left on for a prolonged period.

### Responding to crises

Despite the desire to support people to live well at home, there may be times when admission to hospital is necessary or unavoidable. Hospital admission data shows that average length of stays are longer for people with dementia<sup>27</sup>. Hospitalisation can be a crisis point for people of any age, resulting in loss of confidence and a reduction in levels of mobility and daily functioning and this may be particularly true for people with dementia. As a result, people are all too frequently discharged prematurely to residential care, or face the risk of unplanned readmission because of insufficient support with the transition from hospital to home.

Housing associations can help reduce the pressure on acute hospital beds and provide better outcomes by offering reablement services or step-down accommodation. A good example is Midland Heart's successful service at Sandwell and West Birmingham City Hospital.

### Case study

#### Midland Heart – Ward D47 City Hospital, Sandwell and West Birmingham NHS Hospitals Trust (SWB HT)

Midland Heart has worked with both acute and community trusts to develop reablement units, which are refurbished wards, created to reflect a more homely and less clinical environment. Through a joint trusted assessment team, older people deemed medically fit for discharge and who do not require an acute bed, are placed into the service. The reablement team then creates a personalised support plan to meet the social care needs of the customer, while continuing their discharge journey home. Midland Heart's team of reablement workers delivers a programme of activities focused on wellbeing, confidence-building and independence, as well as ensuring that an ongoing care package is arranged and that any necessary adaptations are fitted to make the transition home go smoothly.

This step-up and step-down refurbished ward, within the main City Hospital building, has 20 flexible community care beds for customers aged 18 or over, though the majority are aged over 65. Its key features include:

- Nurse-led service with staff employed directly by SWB HT – Care Quality Commission registered under the hospital's registration.
- Responsibility for medicine management and care planning lies with the hospital's nursing staff (there is one nurse per shift) while Midland Heart's reablement workers focus on working with customers to achieve the reablement goals outlined in their care and support plans.
- Referrals to D47 are made via a single point access triage service that screens customers' needs and identifies the most appropriate place to meet them. This is solely overseen by the hospital nursing staff. The average age of the patient is 80 and the average length of stay is 9.4 days, with 85% being discharged to their usual place of residence.

<sup>27</sup> Alzheimers Society, Counting the cost: Caring for people with dementia on hospital wards, 2009.

## Building for the future

Housing associations have the expertise and access to the capital needed to provide age-appropriate accommodation, designed to support more independent forms of living for people with dementia. The Housing Learning and Improvement Network's website holds an extensive library of reports, toolkits and case studies about procurement to support specialist housing development, with examples ranging from the building of extra care housing to the effective redesign of existing accommodation<sup>28</sup>.

While investment in extra care schemes and new housing is important, other practical measures can be taken to ensure existing homes and local neighbourhoods become more 'dementia-friendly'. These environmental adaptations can make a big difference<sup>2</sup> and may be introduced on demand to individual households, to a wider neighbourhood or population group, or as part of a planned maintenance and refurbishment programme.

## Case study

### Waltham Forest Housing Association – Improving residents' living environment

Waltham Forest Housing Association (WFHA) took part in a research project focused on small providers' involvement with dementia, run by the Quality of Life Charitable Trust in 2013/14. While WFHA had always been doing a lot of ad hoc work with tenants living with dementia, the research highlighted opportunities to make this work part of its asset management strategy, especially in terms of tenants' living environment.

Waltham Forest Housing Association decided, through planning its cyclical programme of works for 2014/15, to look at two sheltered schemes as a pilot communal redecoration project that could eventually be rolled out across all of its schemes – not just sheltered accommodation.

The aim was to ensure that tenants with dementia were able to live for as long as possible in their own home, and to make accessing facilities as easy as possible – particularly in communal areas, which can often look very similar.

As well as involving tenants from both schemes, WFHA invited the contractor (K&M Decorating), the supplier (Dulux), and Waltham Forest Alzheimer's Society to get involved, advising on painting and decorating the communal areas, upgrading lighting and replacing floor coverings; all work that was already scheduled to be carried out. In order to ensure that the contractors and suppliers had a true understanding of dementia and the needs associated with it, they were invited to attend a Dementia Friends session, alongside six of WFHA's regular day-to-day contractors.

Dulux provided specific mood boards for the two schemes which were used in WFHA's consultation of tenants living there, as well as other tenants who attend the association's monthly Sunshine Club; a social event for those living with dementia, and their neighbours and friends.

WFHA is now working on amending its policy for refurbishing vacant homes, ensuring items such as non-white toilet seats are introduced as standard, as well as better use of colour to differentiate between skirting boards, door frames, walls, floors, sinks and splash backs. As with the pilot, none of these items will incur any additional cost but will make a difference to the independent living of future tenants with dementia.

<sup>28</sup> The Housing Learning and Improvement Network

## Using Public Sector Land

The NHS is one of the largest public landowners in the United Kingdom, with total assets valued at more than £370m<sup>16</sup>. One way in which the NHS might meet some of its £30bn deficit by 2021, while better managing demand for acute services, is to use its land to develop more dementia-friendly housing and alternative community care facilities<sup>29</sup>. The National Housing Federation has been working with the Department of Health to explore how this repurposing of NHS and local authority-owned land might be achieved. A range of pilots are being discussed that will test the types of funding arrangements and accommodation models that might be provided. Further information is available from the Federation's Health Partnership Hub<sup>30</sup>.

## End of Life Care

The housing sector can work proactively with health and social care agencies, and palliative care specialists, to provide better care and more coordinated support as someone with dementia nears the end of their life. This may be through providing equipment and adaptations, offering more flexible forms of accommodation, or through community support. Home Group is one association that has developed a community-based support service for customers who are diagnosed with terminal illness.

### Case study

#### Home Group – A Good Death

Home Group has developed a service that can help support clients who are coming to the end of their lives – or have been diagnosed with a terminal illness – to make practical arrangements and choices that enable them to remain in their own homes for as long as possible.

**Housing staff and volunteers can work with people and their families, where appropriate, to help them plan and prepare for the future.**

They offer a range of practical support, including:

- organising aids and adaptations that will make life easier
- applying for benefits
- putting affairs in order
- learning a new skill
- taking up a new hobby
- providing someone to talk to.

Service users are supported in the use of IT or digital technology, to help them stay in touch with people they can no longer visit. This might include using a webcam, Skype or social media such as Facebook, or starting a video diary. The service is available to anyone in the Tyne and Wear area who is in the last couple of years of their life and wants to continue living in their own home. It can support around 30 clients at any one time, and prioritises those who will most benefit from the service. Home Group accepts referrals directly from the individual requiring support, as well as from their families or carers, or voluntary or statutory agencies. As part of the referral process, the client's needs and circumstances are discussed.

Many of the interventions have little to do with the illness directly. Some are requests for practical help with gardening and cleaning, sorting out paperwork, applying for benefits or planning funeral arrangements. Other support includes social media training and companionship when doing day-to-day activities, like walking a dog.

When someone with dementia has died and other agencies have withdrawn, housing association staff can provide continuity of care and practical and social support to the families left behind. This might include designing new support plans for former carers, providing practical help with funeral arrangements or finances, or discussing potential housing or downsizing options.

<sup>29</sup> National Housing Federation, Surplus NHS land - a best value alternative, 2015.

<sup>30</sup> National Housing Federation, Health Partnership Hub.

# 5 Discussion and key messages

**At a time of budgetary restrictions and a rapidly ageing population, the need to find radically new ways of supporting people to live well in later life is becoming urgent.**

There have been significant policy commitments to move services from hospitals into the community over recent decades, most recently through the NHS Five Year Forward View. However, this has yet to translate into a major shift in service provision or funding allocations. In fact, while the NHS – and especially acute hospital services – have received major cash injections, spending on local authority social care has fallen by 26% in the last five years<sup>1</sup>.

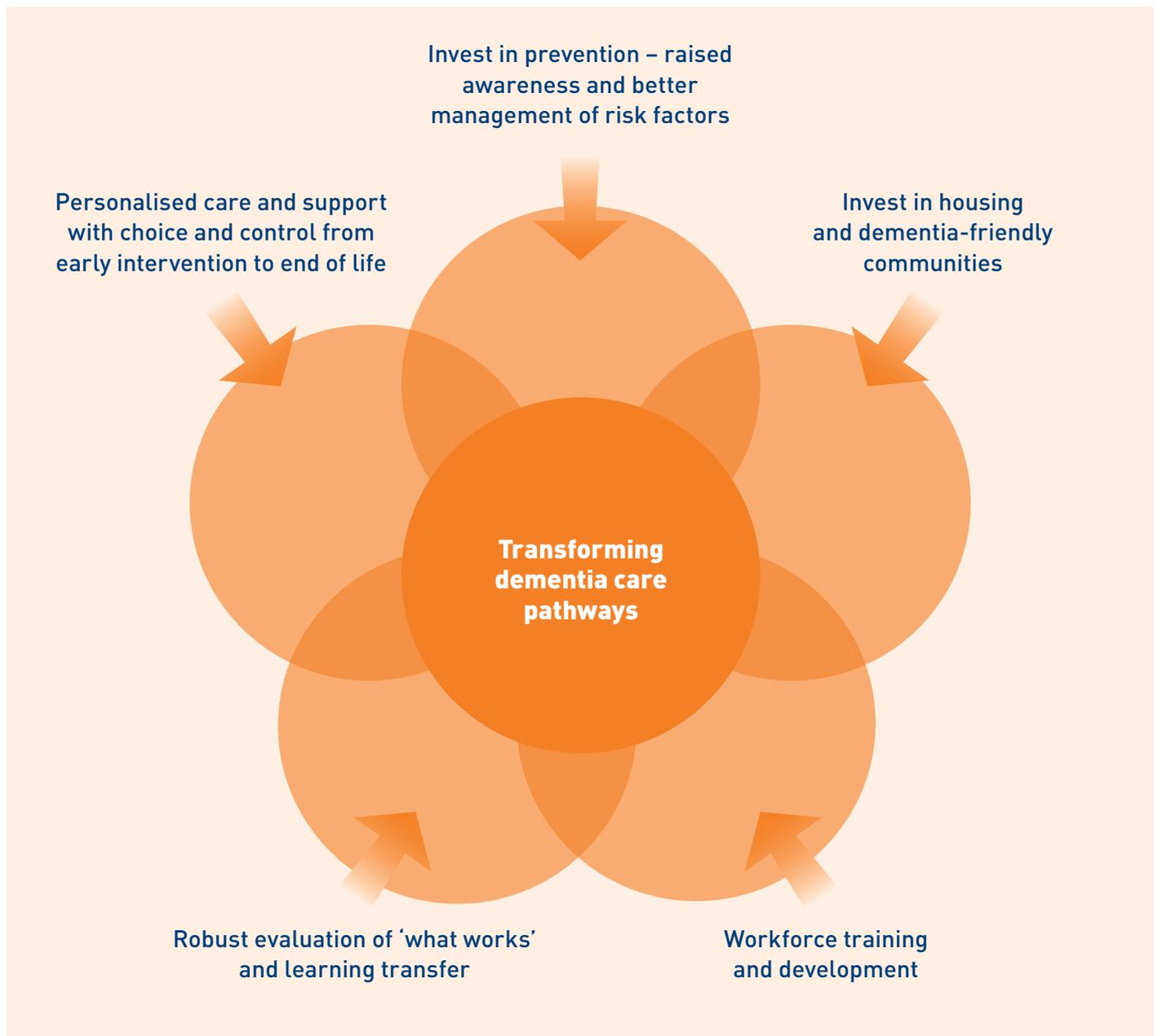
## A prescription for change

This report has identified a number of areas for action that will help transform dementia care pathways, to better support people living with dementia and their families. Housing associations are ideally placed to help health and social care commissioners deliver this change; promoting more integrated service pathways, applying the best evidence to practice, and co-designing support packages with individuals to deliver better health outcomes. A new prescription for change is emerging that can be summarised in six steps.

## Six steps to transformation

There is a need to bring housing, health and social care agencies together at local level to:

- 1. Invest in prevention** – take active steps to reduce the risks of people developing dementia, tackle health inequalities and promote good health across the life course.
- 2. Shift the balance of choice and control** from agencies and professionals to individuals and their families, ensuring individual preferences are understood and honoured.
- 3. Provide a broader range of retirement housing options** and further investment in home adaptations, dementia-friendly neighbourhoods and communities.
- 4. Invest in workforce training and development,** to better support people with dementia.
- 5. Provide flexible service** offers to support people at each stage of their condition, from initial help-seeking, living with dementia and coping with changes, to planning for the end of life.
- 6. Turn the best available evidence into practice** with robust evaluation and effective systems, to transfer learning across different population groups and neighbourhoods at scale and pace.

**Figure 5: Key ingredients for transformation**

No single agency or sector can deliver all of this in isolation, especially in the current economic climate. Cross-sector collaboration, co-production with service users, effective partnership working between commissioners and service providers, joint planning, and strategic investment are essential.

### Checklist for further action

A checklist of recommendations has been produced as a guide to good practice, enabling health and social care commissioners and healthcare providers to make the most of opportunities to work with housing associations.

Responsible	Action	Done
<b>Local authorities and Clinical Commissioning Groups</b>	Make sure housing, planning and commissioning strategies are aligned and include clear plans for meeting the needs of people with dementia.	
<b>Health and Wellbeing Boards</b>	Ensure housing is represented and regularly discussed at health and wellbeing board meetings.	
<b>Housing and planning authorities and health and social care commissioners</b>	Establish a forum to discuss housing market needs and commissioning intentions with providers. Identify potential funding sources for new development.	
<b>Housing and planning authorities and health and social care commissioners</b>	Review available public sector land and discuss the potential for using this to provide new housing and community support facilities with housing providers.	
<b>Public Health teams at regional and local level</b>	Ensure housing providers are involved in public health improvement plans and programmes to tackle health inequality.	
<b>Local authority and health analysts and research teams</b>	Explore ways to link housing data and intelligence to Joint Strategic Needs Assessments and case-finding initiatives at local level.	
<b>Health and social care commissioners</b>	Ensure housing is included in health and social care pathways and commissioning plans from early diagnosis to end of life.	
<b>Health and social care commissioners</b>	Use joint-funding and commissioning mechanisms to test out new ways of working and scale up good practice.	
<b>Health and social care commissioners and workforce development leads</b>	Look for opportunities to jointly invest in workforce training and development between housing, health and social care.	
<b>All agencies</b>	Invest in high quality research and evaluation, and mechanisms for transferring learning into practice.	

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Smith Institute  
Isos Housing  
Gentoo  
Riverside  
Gedling Homes  
Coast & Country  
Notting Hill Housing Trust  
Home Group  
Waltham Forest Housing Association

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