

Dementia-Friendly Communities

12 February 2013

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Summary

This is a briefing on Dementia-Friendly Communities and what they mean for local government.

The briefing covers:

- What is meant by the term 'Dementia-Friendly Communities' and why they are important
- What role Local Authorities can play in promoting and supporting Dementia-Friendly Communities
- Some national and international examples of progress in creating Dementia-Friendly Communities

The briefing may be of use to all councillors and council officers in all tiers of councils working to support people with dementia and their carers, and to create accessible, inclusive places. It may be of particular interest to those who can influence local partners to maximise support for people with dementia and for members of health and wellbeing boards.

Briefing in full

What are Dementia-Friendly Communities?

Dementia-Friendly Communities (whether cities, towns, villages or streets) do as much as possible to remove the barriers to everyday living that people with dementia and their carers face. They also help people with dementia to make the most of their own capabilities, encouraging them and including them in what is going in the community.

Where has the concept come from?

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Gaining currency over the past few years, the concept of Dementia-Friendly Communities has grown out of the longer-established Age-Friendly Movement sponsored by the World Health Organisation. Manchester is a WHO Age-Friendly City and a good example of how, over a ten-year period, the council has led work to develop its approach which covers city planning, housing, neighbourhood, leisure and cultural strategies as well as health and care.

At its core, Manchester's success is built on inclusion of older people, putting them at the centre of defining what age-friendly means and how to implement and promote it. The Valuing Older People programme is a driving force for the delivery of the Age-Friendly City Strategy and has older people leading it and making key decisions in collaboration with councillors, partners and staff. Manchester's strategy can be found [here](#).

National Dementia Strategy

'[Living Well with Dementia: A National Dementia Strategy](#)' was published in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

The emphasis on early diagnosis and the growing impact of this means that more people with dementia are living in communities and are recognised to be so. This shifts our thinking about people with dementia and the support they need from a narrow focus on health and social care to a wider concern across all parts of a community.

Prime Minister's Challenge on Dementia

In March 2012 David Cameron sought to boost the impact of the National Strategy by issuing a personal challenge on dementia. One aspect of that challenge was based on his view that communities need to be more Dementia-Friendly. He said

Not only do [people with dementia] frequently have to battle for diagnosis and support, but everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday – are made difficult because of the limited understanding of dementia in their communities.

He offered an [initial challenge](#) for 20 cities to become dementia friendly by 2015, but this has been widely extended through the promotion of Dementia Action Alliances across the country

Why are Dementia-Friendly Communities Important?

Dementia is not a consequence of old age, but its prevalence increases with ageing. In an ageing population, therefore, more of us will experience dementia, either personally or through the experience of a spouse, parent, grandparent or other relative or friend. In the absence of a cure or effective preventative action, dementia will increasingly become an issue for us individually and socially. If we fail to acknowledge this, the demands on current services and the cost of caring well for people with dementia will become unmanageable. We have to plan for a different future and shift our perception and response to dementia, so that it is more central to our thinking about community life.

For many people, dementia has replaced cancer as the most feared and least talked about terminal illness. It occurs in different forms – the symptoms of Alzheimer’s disease and vascular dementia being markedly different - and individuals and their families respond differently to its many challenges. Dementia is both a physical and mental condition with challenging social consequences for the person with dementia and the people around them. People often feel stigmatised by it and from the early stages, as symptoms appear, can lose social confidence and independence.

Much progress has been made in the last 20 years to create more inclusive communities. Lobbying for ‘child-friendly’ facilities has resulted in much more choice and freedom for families, and the impact of legislation to ensure access and fair treatment for people with disabilities has changed our communities physically and socially. However, people with dementia have not been central to these movements until fairly recently, but this is changing.

What do we need to consider in making communities Dementia-Friendly?

In helping local authorities and their partners to make effective use of the concept of Dementia-Friendly Communities, a model has been developed through action research and collaborative work done for the Local Government Association and for the Joseph Rowntree Foundation. The ‘Four Cornerstones’ model identifies the essential aspects of a community which support people with dementia and their carers.

The Four Cornerstones Model

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The model can be used to help local authorities and their partners to ask questions about their communities to help them assess how Dementia-Friendly they are. Many local authorities focus their thinking about dementia exclusively around social care and the interface with health, but the scope for harnessing support for people with dementia and their carers to live well is much wider.

The following questions under each heading form a basis checklist for assessing how Dementia-Friendly a community might be, and what it is important to focus on in the future.

Place

The Place cornerstone is about the mainly physical aspects of communities, although it can also include how a place feels in terms of ambience or 'feel' : What makes a Dementia-Friendly Place?; what is the focus in terms of scale? - City, Town, Village, Suburb, Street, Home; how welcoming is the Place in terms of:

- environmental Quality – is it clean, litter free, quiet or noisy, calm or busy?
- clarity – Are buildings recognisable, can you find your way around, is there good signage?
- access – can you cross streets easily, is there public transport, easy parking?
- familiarity – What does it have in terms of landmarks (clocktowers, cathedral) distinctive features (market, fountains) historic resonance (seaport, railway town) human scale(places to sit, green routes)

What are the local issues in relation to Place?

Housing – where do people with dementia live, are they well housed, does their housing lead to early admission to care?

Neighbourhood – how do people with dementia (especially those living alone) manage their garden, litter, recycling, waste collection?

Transport – are people with dementia able to use buses and trains? Are people confident to use taxis?

Access – are people isolated geographically? Are they near to facilities but concerned about safe walking routes, crossing points?

People

The People cornerstone can refer to all those people that are significant to a person with dementia on a personal level. Primarily this means family and paid carers, including GPs, wider family and friends, neighbours, and regular callers like the postman and milkman.

What do Dementia-Friendly People Do?

- How aware are they of dementia and what it means generally, and specifically for the person they know?
- What do people do to ensure they don't judge or stigmatise someone with dementia? How can they challenge assumptions about people with dementia?
- Are they understanding and empathetic? Do they support and encourage people to use their abilities as well as helping with things that they can't do?

There is no doubt that GPs are very significant for people with dementia and their families, and those GPs who support early diagnosis, who refer for early support and who socially prescribe access to exercise, social groups and activities are highly valued, but approaches can vary widely still.

People living alone are often hard to identify, diagnose and support and may need more support from the wider community if family and friends are not around.

Resources

Having a narrow definition of the resources which support people with dementia often leads to a focus on specific health and social care services. Much of the potential of a Dementia-Friendly Community is to be found in enabling people with dementia to have access to the everyday resources that we all use in our communities.

What Natural, Physical, Cultural, Commercial, Educational and Personal resources are there in a community which could be available to and support people with dementia?

This might include:

- parks and green space, rivers and lakes, mountains and coasts
- theatres, cinemas, sports facilities, shops, banks and public service offices
- universities, schools, adult learning

- care services, residential and nursing homes, hospitals and clinics, dentists, opticians, chiropodists.

It is important not just to look at the quantity of resources but also their quality and appropriateness. Many of the barriers which stop people with dementia using everyday resources and facilities are about information/marketing/referral (not knowing they exist) or about adaptation/adjustment (making it easier to use by a person with dementia)

Networks

How well does the community work together to support people with dementia? Do things fall between people or organisations? How do we make a complicated system more simple for people with dementia and their carers?

The idea of networks being essential to creating Dementia-Friendly Communities is evident, but often less tangible than the other three 'cornerstones'. Good networks mean that people and organisations are

- effective in sharing understanding
- practical in helping to solve problems
- inclusive in crossing boundaries
- discreet in respecting confidentiality

In simple terms this means that major public service providers need to align their plans and investments to support people with dementia and on the ground they need to co-ordinate what they are doing to make it easier for people to live well.

'Natural' community networks clearly benefit people with dementia, where people share important information about how to support one another and get on and do it.

Local Authorities and Dementia-Friendly Communities

Which Local Authority Services can support people with dementia?

The Four Cornerstones model clearly shows the potential for local authority services beyond health and social care to support people with dementia. It is important that councils take a corporate and strategic approach to dementia, harnessing this potential.

Some ideas and examples for harnessing the contribution of different services might include:

Public Health

Leading on awareness of the demographics of dementia, its growing prevalence, and understanding how to 'live well' with dementia

Adult Social Care

Leading on awareness of different types of dementia, the needs of carers, training for non-specialists who may provide services to people with dementia

Children's Social Care

Raising awareness of intergenerational issues in families, helping children to understand dementia

Education

Working with schools to help children and young people understand dementia, inviting people with dementia and carers in to schools to talk about their experience and their memories

Planning

Leading on place, understanding how the planning process can help people with dementia to access and use places safely and well.

Transport/Highways

Assessing the impact of transport plans on people with dementia, promoting their needs with transport partners. Making places clear through signage.

Housing

Ensuring that people with dementia are well housed and that their housing is adapted to support changing needs. Protecting residents from harassment.

Environmental Services

Enabling people with dementia to keep their environment clean and tidy and to recycle waste

Leisure

Enabling people with dementia to maintain their health and fitness and to enjoy a range of activities with their families and friends

Cultural Services

Supporting people with dementia to enjoy theatre, music and cinema and to continue to participate in these. Enabling access to library services, adapting to meet changing needs. Promoting information about dementia to the wider community

Customer Access

Ensuring that people with dementia can access local services how they choose. Providing training to front line staff about the particular needs of people with dementia

Payment Services

Ensuring that people with dementia and their carers understand and can access payment systems, and that changing needs are responded to.

Economic Development

Working with the local business community to help them to provide better services to people with dementia, including the promotion of 'Dementia-Friendly' rated services if appropriate. Helping to identify people with dementia as contributors to the local economy.

Corporate Services

Ensuring that people with dementia are part of the Equalities Scheme for the council. Promoting the council as a Dementia-Friendly organisation, including the impact of caring from a person with dementia on staff.

How can Elected Members support Dementia-Friendly Communities?

Here are five ways in which elected members at all levels and in the variety of their roles can support Dementia-Friendly Communities

1. Budget Planning and Scrutiny

Be clear about how your investment locally is supporting people with dementia and making your community more Dementia-Friendly. Know the facts about dementia in your area, and ask for analyses about which services support people and what the gaps are.

Monitor and challenge expenditure in terms of outcomes for people with dementia and their families not just in terms of amount spent. Consider ways of reinvesting in community services to help more people earlier, and reduce the costs of responding to crises.

2. Partnership Working

Consider your investment in people with dementia alongside that of other partners in the NHS, voluntary and private sector. Identify the big opportunities to transform services together to get the most out of joint investment and to co-ordinate change.

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Look for ways to influence and encourage partners to do things which are Dementia-Friendly because this is a good thing in itself, but also because there are benefits to be gained.

3. Dementia Champion

Become a 'dementia champion', either formally through involvement in a local Dementia Action Alliance, or informally by speaking out about dementia whenever you can.

Raise awareness of dementia and its impacts on individuals, carers and families and tackle stigma, discrimination and harassment where it arises.

4. Promote what works

Find out about and promote those things that work well for people with dementia and their carers and that offer good value for money.

Share your good practice with others in your own area and across local authorities, building your knowledge and that of others about what a Dementia –Friendly Community really means.

5. Listen to People with Dementia and Their Carers

People with dementia have a voice, sometimes not always as we conventionally think of it – listen to it. Get to know people with dementia and their carers when you visit them in their own homes or meet with them in the community, or in hospital.

If people cannot speak, listen to their carers and families who can often express their wishes. A person is there throughout the stages of a dementia life, so if they cannot speak, make contact in another appropriate way.

How can Local Authorities take the lead in creating Dementia-Friendly Communities?

Health and Well-Being Boards are well placed to take a lead role in the promotion and development of Dementia-Friendly Communities. The drive often comes through sub-groups which focus on Older People and/or Mental Health.

However, it is important that local authorities use their wider corporate and service potential in the promotion and development of Dementia-Friendly Communities, so

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the responsibility for leadership should not be restricted to elected members or officers leading on health and social care.

Council debates, scrutiny investigations, commissions of inquiry, patch walks and visits to good practice sites are all helpful in enabling local authorities to develop their own understanding of what makes a Dementia-Friendly Community and how to move forward in their area. The examples below give some specific pointers about how to approach the topic in creative ways. An LGA toolkit and report from the Joseph Rowntree Foundation provide further support.

Who is leading the way in creating Dementia-Friendly Communities in the UK and beyond?

City of York Council engaged fully with the Joseph Rowntree Foundation action research project 'Creating a Dementia Friendly York'. Senior staff made direct contributions to the project, particularly in leisure, neighbourhood management, and social care commissioning. The Chief Executive and Corporate Management Team engaged directly with the project and engaged elected members in thinking about how it impacted across the whole Council. In direct response to the research, City of York linked the work to its GeniUS York project and invited the whole community to generate ideas about how technology could help people with dementia.

Sheffield Council led local partners through a process of identifying what a Dementia-Friendly Community meant in practice as part of the LGA Ageing Well Programme. The work was overseen at a very high level by the Dementia Programme Board reporting in to the Health and Well-Being Board. Its focus was both strategic - it looked at the way in which planning policy could support the development of Dementia-Friendly Communities and the role of personalised budgets in driving innovation in commissioning, and practical – at the heart of the work was a project on a suburban estate which considered how local services and networks could support people living in the community.

Also part of the LGA Ageing Well work, Hampshire County Council looked at the development of practical tools which partners could use in local communities to identify and address issues which formed barriers for people with dementia and their carers. Engagement with local people and networks of local partners were key factors in understanding issues like isolation and options for addressing them which might include social activities, health interventions and better transport.

Doncaster Council and NHS Doncaster are lead partners piloting a new programme of Accelerated Learning which is supported by the Department of Health and which draws on the Four Cornerstones Model. The programme consists of six workshops

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which help to scope what a Dementia-Friendly Community means locally, then consider Place, People, Resources, Networks in turn and is completed by an action planning session. The Place workshop is a practical walkabout through three town centre sights looking at transport, access and local service issues whilst the People workshop has people with dementia and their carers at its core.

Plymouth University has led over the past few years a comprehensive programme of action to engage local and sub-regional partners in creating a Dementia-Friendly Community. The programme is creating a 'whole system' which looks at the city, suburbs, towns and villages as well as institutions like the University, the Council and the NHS and seeks to promote the concept of Dementia-Friendliness in a comprehensive way. It is practical in that it asks what each place or institution can do, but it is also a 'hearts and minds' approach.

Bruges has been working for several years to position itself as a Dementia-Friendly City and has adopted the 'red knotted handkerchief' symbol used by a number of European cities to signal services which are dementia-friendly. The Council offers support to the whole family affected by dementia and prioritises support at home, but backs this up with a city centre resource where people can drop in for support and respite, as well as residential facilities.

The City Council has led a partnership with local business to promote the red knotted handkerchief scheme, which raises awareness amongst staff, customers and the wider community. In each participant's shop or office resources are made available to help people engage with people with dementia, to start conversations and to offer support. The City has recently commissioned a film which will document how dementia-friendly Bruges is at the moment.

In Japan where the ageing population presents a major challenge, people with dementia are visible in local communities and supported through a 'walking lunch club' which enables them to shop, cook and eat lunch together.

As early diagnosis increases the number of people who have insight and awareness of their dementia, the expansion of online forums and sharing of experience grows and is particularly evident in Australia, the USA and the UK, with strong voices being heard in Torbay and Scotland.

Comment

A Matter of Engagement and Inclusion

Gradually, earlier and better diagnosis has changed the proportion of people with dementia who are living in their own communities and who want, sometimes with

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their carers and families, to have a voice about how they want to live well and what the community can do to enable that. A focus on Dementia-Friendly Communities therefore can be part of the process of engagement and inclusion which local authorities and local partners have with residents and communities.

In response to the National Dementia Strategy and The Prime Minister's Challenge on Dementia, the LGA and the Joseph Rowntree Foundation (the writer of this briefing was a joint author of the report) have published guidance and research which has captured the growing experience of local authorities and their partners in creating Dementia Friendly Communities.

This briefing summarises the latest experience of leading councils in this area, and identifies a critical role for Health and Well-Being Boards in championing the interests of people with dementia and their carers. However the challenge of creating Dementia-Friendly Communities needs a corporate response from local authorities across all its service areas and the engagement of wider public services and voluntary and community sector partners.

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