

**Report of:** Director of Adult Social Services and Director of Public Health

**Report to:** Executive Board

**Date:** January 9<sup>th</sup> 2013

**Subject:** Dementia-friendly Leeds

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Is the decision eligible for Call-In?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

### Summary of main issues

- This report gives an overview of work to date and future plans for dementia-friendly Leeds. The scope of this report covers important developments in health and social care; and steps towards local "dementia-friendly communities", which are intended to improve the everyday experience of living with dementia.
- A dementia-friendly Leeds can only be achieved by the Council working with partner organisations. During 2012, this has included:
  - The Council announcing the commitment to dementia-friendly Leeds (March 2012); and our event for dementia awareness week, "Better lives for people with dementia in Leeds", hosted by West Yorkshire Fire and Rescue.
  - Support from the three Clinical Commissioning Groups in Leeds to allocate £400K of service transformation monies to projects to develop early diagnosis, post-diagnosis support, integrated care, and a skilled workforce. A further £45K has been attracted from NHS regional innovation fund, for collaborative work to reduce inappropriate use of anti-psychotic medication.

### Recommendations

That Executive Board:

- notes the progress made on local strategy and actions to improve the experience of living with dementia in Leeds, including significant investment from local NHS transformation funds.
- affirms the commitment to dementia-friendly Leeds, and requests local strategic partners to support the formation of a Leeds Dementia Action Alliance .
- leads and prioritises this commitment within all areas of Executive responsibility.
- requests all Strategic Directors to develop a proposal which identifies appropriate front-line staff to have dementia-awareness training, and the associated costs.

## Purpose of this report

- 1.1 This report gives an overview of work to date and future plans for dementia-friendly Leeds. The scope of this report covers important developments in health and social care; and steps towards local “dementia-friendly communities”, which benefit the everyday experience of living with dementia. It is an opportunity to develop the Council’s leadership of dementia-friendly Leeds.

## 2 Background information

- 2.1 It is estimated that there are 8,400 people with dementia in Leeds, of whom 4,000 have a diagnosis recorded. Dementia is a term used to describe:
- a set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning. There are many types of dementia. The most common are Alzheimer's disease and vascular dementia. Dementia is progressive, which means the symptoms will gradually get worse*<sup>1</sup>.
- 2.2 *Living Well With Dementia: a National Dementia Strategy* (Department of Health, 2009) is a strong statement of dementia being seen as a national priority. It set out a model to transform health and social care, prioritising early diagnosis and support; improving quality of care and the training of the workforce; and thereby reducing the high costs associated with the condition.
- 2.3 The Department of Health and the Alzheimer’s Society issued the call for dementia-friendly communities in March 2012. Six cities - Bradford, Leeds, Liverpool, Plymouth, Sheffield and York - responded to this call and were announced at the Alzheimer’s Society’s *Dementia 2012* event on 26<sup>th</sup> March<sup>2</sup>.
- 2.4 The Alzheimer’s Society has led the formation of the Dementia Action Alliance (DAA) as a national organisation which brings together “organisations from across the charity, public and private sector to radically improve the lives of people with dementia”<sup>3</sup>. Leeds City Council has joined the DAA, and the Council’s Director of Adult Social Services addressed the launch of the Yorkshire and Humberside Dementia Action Alliance on November 16<sup>th</sup>.

## 3 Main issues

- 3.1 The Council and local NHS organisations, working with a broad range of stakeholders, have produced a draft strategy, *Living Well With Dementia in Leeds*, to be finalised with a published action plan early in 2013. It recognises that:
- Dementia is a long-term condition, which can be managed to maintain well-being; and usually co-exists with other long-term conditions;
  - Support must be co-ordinated throughout the “dementia journey”, from awareness of early signs and symptoms, through diagnosis and early intervention, to care through the advanced stages and end of life care.
  - Family members and carers are often the most important support that a person with dementia has, and have specific needs arising from the impact of dementia on relationships, decision-making, and daily living.

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<sup>1</sup> <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120>

<sup>2</sup> <http://mediacentre.dh.gov.uk/2012/03/26/becoming-world-leader-for-dementia-friendly-society-care-research/>

<sup>3</sup> <http://www.dementiaaction.org.uk/>

- 3.2 The three Clinical Commissioning Groups (CCGs) in Leeds have all engaged positively with the development of the local dementia strategy, and the approach of including dementia as part of integrated health and social care developments. Leeds North CCG leads on dementia on behalf of the collaborative arrangements between the three CCGs. As Clinical Director of Leeds North CCG, Dr Manjit Purewal has lead responsibility for dementia.
- 3.3 The three CCGs in Leeds will be required to set a quantified ambition for diagnosis rates. This is the percentage of people estimated to have dementia in the population, who are actually recorded on GP registers as having a diagnosis of dementia. In Leeds, the current figure is 47%, compared to a national average of 43%<sup>4</sup>. The NHS will not set a single national target, because of the wide variation in diagnosis rates. Instead, the Department of Health will *support clinical commissioning groups to set a local ambition to improve their dementia diagnosis rate, commission sufficient memory services to deliver their ambition, and to track and demonstrate their progress; and ....use the NHS Outcomes Framework 2013/14 to measure progress on diagnosis rates*<sup>5</sup>.
- 3.4 The following priorities have been identified for improving health and social care in Leeds, the first four of which will be supported by one-off investment of local service transformation funds:
- Increasing early detection and diagnosis, by support and training for GPs, and improvements to memory clinic services.
  - Ensuring that after diagnosis, there is a clear offer of support and treatment to maintain well-being and independence as far as the condition allows.
  - Improving integrated care for people with more complex needs and risks, which arise from a combination of dementia, long-term conditions, and frailty.
  - Achieving the standard for workforce quality, for health and social care, set by the National Institute for Clinical Excellence – that people with dementia are cared for by appropriately-trained staff.
  - Better support with emotional and psychological needs, and reduced use of anti-psychotic medication; supported by investment of £45K NHS regional innovation fund.
  - A local campaign to improve public awareness, and promoting positive attitudes towards people living with dementia.
  - Leeds Teaching Hospitals Trust to improve ward environments, in line with the NHS Call To Action *The Right Care – developing dementia-friendly hospitals*<sup>6</sup>.
  - A dementia needs assessment for the Leeds population, to improve our understanding of local needs, as part of the Joint Strategic Needs Assessment.
- 3.5 Alongside these priorities, Leeds is committed to developing dementia-friendly communities and involving people living with dementia in this process. This requires the greatest degree of engagement from a wide range of businesses and organisations outside health and social care, most of whom never have considered their role in enabling people to live well with dementia.

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<sup>4</sup> <http://www.alzheimers.org.uk/dementiamap>

<sup>5</sup> <https://www.wp.dh.gov.uk/dementiachallenge/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf>

<sup>6</sup> [www.dementiaaction.org.uk/info/2/action\\_plans/165/the\\_right\\_care\\_creating\\_dementia\\_friendly\\_hospitals](http://www.dementiaaction.org.uk/info/2/action_plans/165/the_right_care_creating_dementia_friendly_hospitals)

- 3.6 The Alzheimer's Society has produced a consultation paper (October 2012) on the recognition process for dementia friendly communities<sup>7</sup>. It proposes that a dementia-friendly community should:
- a. Have a Dementia Action Alliance or similar effective network;
  - b. support from recognised local leaders championing the work, including from the statutory and commercial sectors;
  - c. have analysed the key issues that need to be adapted / changed;
  - d. involve people living with dementia, taking account of lived experiences and needs.
  - e. identified businesses and organisations which are priority for awareness / training, with publicly-accessible records of those who have completed it.
  - f. organisations providing information about dementia and local services, with a range of outlets and formats.
- 3.7 We have made progress on each these specific criteria:
- a. We have set up a "Dementia-Friendly Leeds Forum", chaired by the Deputy Executive Member for Adult Social Care. Membership is on an informal basis and mainly representatives of neighbourhood networks and other voluntary and community groups.
  - b. Leeds Initiative Board, representing statutory and business sectors, has supported dementia as a priority at its February 2012 meeting.
  - c. Our "Better Lives For People With Dementia In Leeds" event in May 2012, included a workshop on dementia-friendly communities. This suggested that priorities should include awareness-raising with supermarkets and transport providers; promoting intergenerational work; and exploring whether a 'self-identification' scheme would be helpful. This would enable a person to show a 'passport'-type document to explain one's condition and needs, in case of difficulties.
  - d. We have started to involve people with dementia via the above event and the Dementia-Friendly Leeds Forum. We will develop and support this by working with Leeds Involving People.
  - e. The Leeds Alzheimer's Society has delivered awareness-raising talks at two meetings of supermarket managers and staff; and the Chief Executive has written to the bus operating companies to offer the opportunity of awareness-raising for drivers.
  - f. Information is available via the Leeds branch of the Alzheimer's Society, health and social care organisations, and by telephone and online from the Leeds Directory. Leeds Library Services has set up information sessions about dementia, making use of its meeting spaces and information resources.
- 3.8 Leeds Neighbourhood Networks and other community groups have been developing services for people with dementia, and supporting people with dementia to take part in groups and activities. Leeds currently has: 17 dementia cafes; 2 dementia advisers; 2 carer support workers; 3 carer support groups; 5 "singing for the brain" groups; a peer support network with links to libraries and art gallery; reminiscence and other creative activities / projects.
- 3.9 The "Good Ideas for Dementia" small grants programme is supporting 18 groups to run projects offering community awareness, creative and therapeutic activities, and

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<sup>7</sup> [www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1500](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1500)

support groups. In January and February there will be training courses for staff and volunteers on dementia awareness, how to include and involve people with dementia, and reminiscence.

- 3.10 Success in working across Council Directorates has been demonstrated by the Dementia Peer Support Service, provided by Adult Social Care has working in partnership with other Council directorates. A cultural partnership with Leeds Museums, Galleries and Libraries and West Yorkshire Playhouse enables people with dementia structured, safe and supported access to learning, reminiscence, history, arts and drama; and to resources and venues in our City of Leeds that may otherwise be difficult for some individuals to access. The partnership increases opportunities for people which are often restricted or lost during the experience of dementia. For example:
- *Thinking Art* - this group produced an art installation which went on display in Leeds Art Gallery and The Discovery Centre.
  - *Playing the part* - a creative arts project working with masks. Each participant went on to design and produce their own mask which was then displayed in The Discovery Centre.
  - *Musical Memories* - a support group based around the history of musicals, modern musicals and art, leading to the group writing and recording a song.
  - *Puppeteers* - an opportunity to explore the theatre, production, history, reminiscence and make puppets. The group has made a short film to create and tell a story.
- 3.11 There is a range of intergenerational work in Leeds, including an initiative between Bramley Elderly Action and Raynville Primary School which involves people with dementia meeting weekly with a group of children, which has been sustained since 2009<sup>8</sup>. A dementia-friendly Leeds would see such initiatives becoming widespread across the city, towns and villages. Leeds Older People's Forum has held an event to disseminate the learning from this project, and identified that the main challenge is to engage more schools and young people's organisations.
- 3.12 It is envisaged that Leeds should have at least one innovative project to develop a dementia-friendly environment outside health and social care. This would introduce eg. clear signage and good lighting, which would help many people, regardless of dementia. Signage is already used in a range of health and care settings, provided by a Leeds-based company. Opportunities are being explored to pilot a dementia-friendly environment in a local supermarket or other setting.

## **4 Corporate Considerations**

### **4.1 Consultation and Engagement**

- 4.1.1 This has taken place with individuals who are living with dementia, third sector organisations including the local dementia advocacy provider, NHS and social care providers and clinicians. Leeds Alzheimer's Society and the Council's Peer Support Service in particular enable us to access views from people living with dementia. Leeds Involving People has agreed to provide support for people with dementia to become involved in dementia-friendly Leeds.

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<sup>8</sup> <http://www.olderpeopleleeds.info/clients/infostore/files/NAA%20Newsletter%203rd%20Edition.pdf>

## **4.2 Equality and Diversity / Cohesion and Integration**

- 4.2.1 Dementia is itself a condition which causes cognitive and other impairment, and affects a diverse range of local people. It is suggested by community groups and professionals that poor understanding of the condition, and stigma attached to it, may be a particular concern in some minority ethnic communities. It is estimated that there are 100-200 older people living with dementia in Leeds Caribbean, Irish, Jewish, and south Asian communities.
- 4.2.2 Age is the main risk factor linked to dementia, and thus dementia is most prevalent in the more affluent and rural areas within the Council boundary, where life expectancy is longest. However, at any given age, the risk of developing dementia is highest in the more deprived, inner-city areas of Leeds.

## **4.3 Council policies and City Priorities**

- 4.3.1 Dementia-friendly Leeds is linked to the aspiration to become “Best City...”, not only for health and well-being, but all five themes in the City Priority Plan. The Chief Executive of the Council spoke to this theme when addressing the event “Better Lives For People With Dementia In Leeds” during dementia awareness week in May 2012.
- 4.3.2 It is proposed that Leeds City Council should demonstrate its commitment to dementia-friendly Leeds, by ensuring that customer-facing staff have dementia awareness training. This training is already available for adult social care staff, and for staff and volunteers in Neighbourhood Networks and other local organisations.

## **4.4 Resources and value for money**

- 4.4.1 The National Dementia Strategy emphasises the high cost of dementia to health, social care and wider society. It is based on supporting people to live well with dementia from the earliest stages, to maintain well-being and reduce costs associated with eg. avoidable admissions to hospital and care homes.
- 4.4.2 The resources required to support dementia-friendly Leeds are, in the main, to be found from people and organisations acknowledging that dementia is “everybody’s business”, and contributing time and effort accordingly. The formation of a Leeds Dementia Action Alliance is proposed as a means to involve partner organisations, develop the programme of work, co-ordinate local action and make best use of others’ time and effort. This will require resource to work effectively.
- 4.4.3 The delivery of half-day dementia awareness training for customer-facing staff in the Council would cost c. £45 per person (not including any costs of staff cover during training). Further work would be required to assess numbers of staff and costs.

## **4.5 Legal Implications, Access to Information and Call In**

- 4.5.1 There are no direct legal implications of this report. There is no confidential information or implications regarding access to information. It is subject to call-in.

## **4.6 Risk Management**

- 4.6.1 “Dementia-friendly communities” is a simple idea, but in practice it is a complex task which requires the commitment of many businesses and other organisations beyond the direct authority of the Council. This gives rise to the risk of negative public perceptions of the aim. The approach outlined in section 3 above is proposed to manage this risk, by including both simple and achievable actions, alongside winning the commitment of other organisations, and exploring innovations.

## **5 Conclusions**

- 5.1 In 2013, Leeds will see investment in improvements to health and social care for people living with dementia. Our commitment to dementia-friendly communities complements this with wider social action to improve experience of everyday life with dementia. Initial steps have been taken in line with the framework set by the national Alzheimer’s Society, but there is much to do. Potential next steps in Leeds are:
- Supporting stronger involvement of people living with dementia, families and carers.
  - Supporting the formation of a Leeds Dementia Action Alliance, with wider membership across business, community and statutory organisations, and supporting local towns and villages to sign up and identify their own leaders and ‘champions’ for dementia.
  - Leeds City Council to take a lead in ensuring a dementia-friendly approach, including dementia-awareness training for customer-facing staff.
  - Developing awareness-raising work with supermarkets and transport providers.
  - A “flagship” project to pilot a dementia-friendly environment in a supermarket or other well-used building.
  - Supporting the development of intergenerational work, including steps to involve more schools.

## **6 Recommendations**

- 6.1 That Executive Board:
- notes the progress made on local strategy and actions to improve the experience of living with dementia in Leeds, including significant investment from local NHS transformation funds.
  - affirms the commitment to dementia-friendly Leeds, and requests local strategic partners to support the formation of a Leeds Dementia Action Alliance .
  - leads and prioritises this commitment within all areas of Executive responsibility.
  - requests all Strategic Directors to develop a proposal which identifies appropriate front-line staff to have dementia-awareness training, and the associated costs.

## **7 Background documents<sup>9</sup>**

- 7.1 None.

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<sup>9</sup> The background documents listed in this section are available to download from the Council’s website, unless they contain confidential or exempt information. The list of background documents does not include published works.