

Scrutiny Inquiry Panel - Dementia Friendly Southampton

Thursday, 24th September,
2015

at 5.30 pm

PLEASE NOTE TIME OF MEETING

Conference Room 3 - Civic Centre

This meeting is open to the public

Members

Councillor Burke
Councillor Coombs
Councillor Houghton
Councillor Lewzey
Councillor McEwing
Councillor Painton
Councillor Parnell

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PUBLIC INFORMATION

Role of Scrutiny Panel Inquiry – Dementia Friendly Southampton

The Overview and Scrutiny Management Committee have instructed the Scrutiny Panel to undertake an inquiry into Dementia Friendly Southampton.

Purpose: To review how far the Council is progressing in making Southampton a dementia friendly city and to identify further actions needed using the recognised framework developed by Alzheimer's Society.

Southampton City Council's Priorities

- Jobs for local people
- Prevention and early intervention
- Protecting vulnerable people
- Affordable housing
- Services for all
- City pride
- A sustainable Council

Use of Social Media:- The Council supports the video or audio recording of meetings open to the public, for either live or subsequent broadcast. However, if, in the Chair's opinion, a person filming or recording a meeting or taking photographs is interrupting proceedings or causing a disturbance, under the Council's Standing Orders the person can be ordered to stop their activity, or to leave the meeting.

Public Representations

At the discretion of the Chair, members of the public may address the meeting about any report on the agenda for the meeting in which they have a relevant interest.

Smoking policy – the Council operates a no-smoking policy in all civic buildings.

Mobile Telephones – please turn off your mobile telephone whilst in the meeting.

Fire Procedure – in the event of a fire or other emergency a continuous alarm will sound and you will be advised by Council officers what action to take.

Access – access is available for the disabled. Please contact the Democratic Support Officer who will help to make any necessary arrangements.

Dates of Meetings: Municipal Year

2015	2016
24 September	21 January
29 October	25 February
19 November	7 April
3 December	

CONDUCT OF MEETING

TERMS OF REFERENCE

The general role and terms of reference of the Overview and Scrutiny Management Committee, together with those for all Scrutiny Panels, are set out in Part 2 (Article 6) of the Council's Constitution, and their particular roles are set out in Part 4 (Overview and Scrutiny Procedure Rules – paragraph 5) of the Constitution.

BUSINESS TO BE DISCUSSED

Only those items listed on the attached agenda may be considered at this meeting.

RULES OF PROCEDURE

The meeting is governed by the Council Procedure Rules and the Overview and Scrutiny Procedure Rules as set out in Part 4 of the Constitution.

QUORUM

The minimum number of appointed Members required to be in attendance to hold the meeting is 3.

DISCLOSURE OF INTERESTS

Members are required to disclose, in accordance with the Members' Code of Conduct, **both** the existence **and** nature of any "Disclosable Pecuniary Interest" or "Other Interest" they may have in relation to matters for consideration on this Agenda.

DISCLOSABLE PECUNIARY INTERESTS

A Member must regard himself or herself as having a Disclosable Pecuniary Interest in any matter that they or their spouse, partner, a person they are living with as husband or wife, or a person with whom they are living as if they were a civil partner in relation to:

- (i) Any employment, office, trade, profession or vocation carried on for profit or gain.
- (ii) Sponsorship:

Any payment or provision of any other financial benefit (other than from Southampton City Council) made or provided within the relevant period in respect of any expense incurred by you in carrying out duties as a member, or towards your election expenses. This includes any payment or financial benefit from a trade union within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992.

(iii) Any contract which is made between you / your spouse etc (or a body in which the you / your spouse etc has a beneficial interest) and Southampton City Council under which goods or services are to be provided or works are to be executed, and which has not been fully discharged.

(iv) Any beneficial interest in land which is within the area of Southampton.

(v) Any license (held alone or jointly with others) to occupy land in the area of Southampton for a month or longer.

(vi) Any tenancy where (to your knowledge) the landlord is Southampton City Council and the tenant is a body in which you / your spouse etc has a beneficial interests.

(vii) Any beneficial interest in securities of a body where that body (to your knowledge) has a place of business or land in the area of Southampton, and either:

- a) the total nominal value for the securities exceeds £25,000 or one hundredth of the total issued share capital of that body, or

- b) if the share capital of that body is of more than one class, the total nominal value of the shares of any one class in which you / your spouse etc has a beneficial interest that exceeds one hundredth of the total issued share capital of that class.

Other Interests

A Member must regard himself or herself as having an 'Other Interest' in any membership of, or occupation of a position of general control or management in:

Any body to which they have been appointed or nominated by Southampton City Council

Any public authority or body exercising functions of a public nature

Any body directed to charitable purposes

Any body whose principal purpose includes the influence of public opinion or policy

Principles of Decision Making

All decisions of the Council will be made in accordance with the following principles:-

- proportionality (i.e. the action must be proportionate to the desired outcome);
- due consultation and the taking of professional advice from officers;
- respect for human rights;
- a presumption in favour of openness, accountability and transparency;
- setting out what options have been considered;
- setting out reasons for the decision; and
- clarity of aims and desired outcomes.

In exercising discretion, the decision maker must:

- understand the law that regulates the decision making power and gives effect to it. The decision-maker must direct itself properly in law;
- take into account all relevant matters (those matters which the law requires the authority as a matter of legal obligation to take into account);
- leave out of account irrelevant considerations;
- act for a proper purpose, exercising its powers for the public good;
- not reach a decision which no authority acting reasonably could reach, (also known as the "rationality" or "taking leave of your senses" principle);
- comply with the rule that local government finance is to be conducted on an annual basis. Save to the extent authorised by Parliament, 'live now, pay later' and forward funding are unlawful; and
- act with procedural propriety in accordance with the rules of fairness.

AGENDA

Agendas and papers are now available via the City Council's website

1 ELECTION OF CHAIR AND VICE-CHAIR

Subject to the Annual Council Meeting not appointing the Committee's Chair and Vice Chair, to elect the Chair and Vice Chair for the Municipal Year 2015/16.

2 APOLOGIES AND CHANGES IN PANEL MEMBERSHIP (IF ANY)

To note any changes in membership of the Panel made in accordance with Council Procedure Rule 4.3.

3 DECLARATION OF PARTY POLITICAL WHIP

Members are invited to declare the application of any party political whip on any matter on the agenda and being scrutinised at this meeting.

4 DECLARATIONS OF SCRUTINY INTEREST

Members are invited to declare any prior participation in any decision taken by a Committee, Sub-Committee, or Panel of the Council on the agenda and being scrutinised at this meeting.

5 STATEMENT FROM THE CHAIR

6 INQUIRY TERMS OF REFERENCE (Pages 1 - 8)

A report of the Head of Legal and Democratic Services inviting the Panel to note the terms of reference and to amend and approve a final version of the outline inquiry project plan.

7 INTRODUCTION TO THE INQUIRY (Pages 9 - 108)

Report of the Director of Quality and Integration introducing the invited guests for the inaugural meeting of the scrutiny inquiry.

Wednesday, 16 September 2015

HEAD OF LEGAL AND DEMOCRATIC SERVICES

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Agenda Item 6

DECISION-MAKER:	SCRUTINY INQUIRY PANEL		
SUBJECT:	INQUIRY TERMS OF REFERENCE		
DATE OF DECISION:	24 TH SEPTEMBER 2015		
REPORT OF:	HEAD OF LEGAL AND DEMOCRATIC SERVICES		
<u>CONTACT DETAILS</u>			
AUTHOR:	Name:	Mark Pirnie	Tel: 023 8083 3886
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STATEMENT OF CONFIDENTIALITY

None

BRIEF SUMMARY

On 13th August 2015 the Overview and Scrutiny Management Committee (OSMC) agreed the terms of reference for a scrutiny inquiry examining how Southampton can become a dementia friendly city.

The outline project plan for the inquiry identifies themes for each meeting and potential consultees. This report invites the Panel to note the terms of reference and to amend and approve a final version of the outline inquiry project plan.

RECOMMENDATION:

- (i) That the terms of reference set out in Appendix 1 be noted.
- (ii) That the Panel discuss, amend and approve a final version of the attached outline inquiry project plan allowing for sufficient flexibility and the availability of suitable witnesses.

REASON FOR REPORT RECOMMENDATIONS

1. To enable the Scrutiny Panel to commence the evidence gathering process.

ALTERNATIVE OPTIONS CONSIDERED AND REJECTED

2. There are numerous options that could be included within the attached draft terms of reference. The version attached reflects the feedback from both the OSMC and members of the Scrutiny Inquiry Panel.

DETAIL (Including consultation carried out)

3. The OSMC agreed the outline terms of reference for a scrutiny review examining how Southampton can become a dementia friendly city on 13th August 2015.
4. Panel members are invited to note the terms of reference and to amend and approve a final version of the attached outline inquiry project plan. The approved plan will then provide the structure to the subsequent meetings of this review, allowing for flexibility and the availability of suitable witnesses.

5. The outline inquiry project plan identifies that the review will be conducted over 7 meetings of the Scrutiny Panel. It is envisaged that each of the inquiry meetings will last for approximately two hours.

RESOURCE IMPLICATIONS

Capital/Revenue

6. Resources to support the scrutiny review will come from existing budgets.

Property/Other

7. N/A.

LEGAL IMPLICATIONS

Statutory power to undertake proposals in the report:

8. The duty to undertake overview and scrutiny is set out in Part 1A Section 9 of the Local Government Act 2000.

Other Legal Implications:

9. None

POLICY FRAMEWORK IMPLICATIONS

10. The outcome of the scrutiny review may contribute to the following priorities within the Council Plan:
 - Protecting vulnerable people
 - Prevention and early intervention
 - City Pride

KEY DECISION? No

WARDS/COMMUNITIES AFFECTED:	None directly as a result of this report
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SUPPORTING DOCUMENTATION

Appendices

1.	Terms of Reference and Inquiry Plan
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Documents In Members' Rooms

1.	None
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Equality Impact Assessment

Do the implications/subject of the report require an Equality Impact Assessment (EIA) to be carried out.	Dependent upon forward plan item
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Other Background Documents

Equality Impact Assessment and Other Background documents available for inspection at:

Title of Background Paper(s)	Relevant Paragraph of the Access to Information Procedure Rules / Schedule 12A allowing document to be Exempt/Confidential (if applicable)
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1.	None	
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Making Southampton a Dementia Friendly City Terms of Reference and Inquiry Plan

1. Scrutiny Panel membership:

- a. Councillor Coombs
- b. Councillor Burke
- c. Councillor Houghton
- d. Councillor Lewzey
- e. Councillor McEwing
- f. Councillor Painton
- g. Councillor Parnell

2. Purpose:

To review how far we are progressing in making Southampton a dementia friendly city, and to identify further actions needed using the recognised framework developed by Alzheimer's Society.

3. Background:

- In March 2012 the Department of Health published the Prime Ministers Challenge to deliver major improvements in dementia care and research by 2015.
- In August 2013 Alzheimer's Society produced 'Building dementia-friendly communities: a priority for everyone. In this report a dementia friendly community is described as:

'A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day to day lives.'

- In February 2015 the Department of Health published the Prime Ministers Challenge on Dementia 2020 which sets out the programme of action to deliver sustained improvements in health and care, create dementia friendly communities, and boost dementia research.
- The estimated number of people with dementia in Southampton is 2618 (March 2015). This figure has been rising and is expected to increase further in line with an increase in the over 65 population which is set to increase by 11% between 2012 and 2019.
- Southampton has a diagnosis rate of 65%; there is a need to review and improve the provision of post diagnostic support that is available, which includes making our city dementia friendly.
- The City has a dementia partnership that has good attendance from a range of health and voluntary sector agencies. There is an aspiration within the partnership to extend the work into a formal framework that will enable delivery of dementia friendly community in a more co-ordinated way, to include wider representation, and to be appropriately resourced.

4. Objectives:

- a) To understand how far we are progressing in making Southampton a dementia friendly city, and to identify further actions needed.
- b) To align our work and priorities to the existing framework in place: Alzheimer's Society building dementia-friendly communities - a priority for everyone.
- c) To support the registration to the recognition process for dementia friendly communities and achieve to the 'working to become dementia friendly' symbol.

5. Methodology:

- a) Working within the existing framework - Alzheimer's Society building dementia friendly communities: a priority for everyone
- b) Benchmarking our current progress against framework
- c) Seek stakeholder views, including those living with dementia and their carers through attendance at existing networks
- d) Undertake desktop research
- e) Identify best practice

6. Proposed Timetable:

Seven meetings between September 2015 and March 2016.

7. Inquiry Plan (subject to the availability of speakers)

Meeting 1: 24th September 2015

- Introduction, context and background – Overview of Alzheimer's Society building dementia-friendly communities: a priority for everyone, and recognition process.
- Review current progress against recognition framework in Southampton.

To be invited:

- Cabinet Member for Health and Adult Social Care
- Penny Ford, Dementia Action Alliances Projects Manager, Alzheimer's Society
- Sara Miles, Programme Manager, Dementia Friendly Communities, Alzheimer's Society
- Debbie Morshead, Andover Mind, Dementia Friendly Hampshire Project Lead
- Barry Dickinson, Commissioner, Integrated Commissioning Unit, Portsmouth City Council & NHS Portsmouth Clinical Commissioning Group

Between meetings 1 and 2 – Consultation event engaging people with dementia and their carers.

Meeting 2: 29th October 2015

To develop an understanding, and identify best practice in the following areas:

- **Challenge stigma and build understanding** – work to breakdown the stigma of dementia, including seldom heard communities, and increase awareness and understanding of dementia
- **Acknowledge potential** – ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities, build on the goodwill in the general public to make communities dementia friendly
- **Practical support to enable engagement in community life, and accessible community activities** – Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.

To be invited:

- Karen Cotton, Lead Admiral Nurse, Solent NHS Trust
- Sharon Harwood, Integrated Service Matron/Learning Facilitator, Southern Health NHS Foundation Trust
- Gary Walker, Services Manager Team South, Alzheimer's Society
- Sue Dewhirst, Public Health Support Manager, Public Health England South East
- Sally Denley, Public Health Development Manager, Southampton City Council
- Community Solutions Group, Southampton Integrated Commissioning Unit
- Arts Council South West

Meeting 3: 19th November 2015

To develop an understanding, and identify best practice in the following areas:

- **Community based solutions** – support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive, high quality care homes. Community based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.

To be invited:

- Head of Housing Services, Southampton City Council
- Supported Services Manager, Southampton City Council
- Quality Lead for Residential and Care Homes, Southampton Integrated Commissioning Unit
- Community Solutions Group, Southampton Integrated Commissioning Unit

Meeting 4: 3rd December 2015

To develop an understanding, and identify best practice in the following areas:

- **Respectful and responsive business and services** – promote awareness of dementia in all shops, businesses and services so all staff demonstrated understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business.

- **Consistent and reliable travel options** – ensure that people with dementia can be confident that transport will be consistent, reliable and responsive and respectful to their needs.

To be invited:

- Katherine Barbour, Senior Project Manager, Wessex Academic Health Science Network
- Phil Williams, Age UK Southampton
- Dianne Bizley, Solent Mind
- Sara Baily, Voluntary Sector Liaison Manager, Southampton Integrated Commissioning Unit
- Local bus operators
- Travel and Transport, Southampton City Council

Meeting 5: 21st January 2016

To develop an understanding, and identify best practice in the following areas:

- **Ensure an early diagnosis** – ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.

To be invited:

- Adult Social Care, Southampton City Council
- Dr Sue Robinson, Clinical Chair, Southampton City Clinical Commissioning Group
- Dr Cliff Howells, Clinical Programme Lead for Mental Health, Southampton City Clinical Commissioning Group
- Debbie Robinson, Head of Integrated Care, Southern Health NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust

Meeting 6: 25th February 2016

To develop an understanding, and identify best practice in the following areas:

- **Easy to navigate environments** – ensure that the physical environment is accessible and easy to navigate for people with dementia

To be invited:

- Housing, Southampton City Council
- Planning Policy, Conservation and Design, Southampton City Council
- Dr Ruth Bartlett, University of Southampton, Dementia Action Research and Education Network

Between the final evidence gathering meeting and agreeing the final report – Consultation event discussing emerging recommendations with people with dementia and their carers.

Meeting 7: Date TBC

To approve the final report of the inquiry and recommendations.

Agenda Item 7

DECISION-MAKER:	SCRUTINY INQUIRY PANEL		
SUBJECT:	INTRODUCTION TO THE INQUIRY		
DATE OF DECISION:	24 th SEPTEMBER 2015		
REPORT OF:	DIRECTOR OF QUALITY AND INTEGRATION		
<u>CONTACT DETAILS</u>			
AUTHOR:	Name:	Amanda Luker	Tel: 023 8072 5568
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Director	Name:	Stephanie Ramsey	Tel: 023 8029 6941
	E-mail:	Stephanie.Ramsey@southampton.gov.uk	

STATEMENT OF CONFIDENTIALITY

None

BRIEF SUMMARY

For the opening meeting of the 'Making Southampton a Dementia Friendly City Inquiry' the Cabinet Member for Health and Adult Social Care has been invited to outline the Executive's position on making Southampton a dementia friendly city.

Work and priorities will be aligned to the existing framework in place: Alzheimer's Society building dementia-friendly communities - a priority for everyone. An overview of the framework, attached as Appendix 1, will be delivered by independent expert, Penny Ford from Alzheimer's Society. This will be followed by an overview of the experience of implementation in other geographical areas; this will be delivered by invited experts from Hampshire, Debbie Moreshead, Andover Mind and Barry Dickinson, Portsmouth Integrated Commissioning Unit (Portsmouth attendance to be confirmed).

Amanda Luker, Southampton City Integrated Commissioning Unit will then provide an overview of current progress against the recognition framework in Southampton.

RECOMMENDATION:

- (i) The Panel is recommended to consider the comments made by the Cabinet Member for Health and Adult Social Care and the invited experts and use the information provided as evidence in the review.

REASON FOR REPORT RECOMMENDATIONS

1. To enable the Panel to compile a file of evidence in order to formulate findings and recommendations at the end of the review process.

ALTERNATIVE OPTIONS CONSIDERED AND REJECTED

2. None.

DETAIL (Including consultation carried out)

3. Councillor Shields, Cabinet Member with responsibility for Health and Adult Social Care, has been invited to outline the Executive's position on making Southampton a dementia friendly city.
4. The Alzheimer's Society has developed a framework that has been implemented across the country, Alzheimer's Society building dementia-friendly communities - a priority for everyone.
5. The process is designed to enable communities to be publicly recognised for their work towards becoming dementia-friendly. Once registration to the recognition process has been accepted, organisations will then be granted use of the 'working to become dementia friendly' symbol issued by Alzheimer's Society.
6. The National Dementia Action Alliance is hosted by the Alzheimer's Society and brings together members with a national footprint, working to improve the lives of people with dementia and their carers within health and social care. The National Dementia Action Alliance Secretariat brings change through building a reciprocal relationship with members. A Local Dementia Action Alliance brings together regional and local members to improve the lives of people with dementia in their area. They are seen as the local vehicle to develop dementia friendly communities.
7. Debbie Moreshead, Project Lead, Dementia Friendly Hampshire has been working across the County, and the programme has included the creation of; the Hampshire Dementia Action Alliance, Dementia Ambassadors, Dementia Friendly High Streets, Awareness Raising initiatives, Peer Support groups and Dementia Action Groups. Debbie has been invited to present experiences from Hampshire, to talk to the Panel about lessons learnt during implementation, and to provide her view about what has worked well, and what she would have done differently.
8. Amanda Luker will provide an overview of the current progress against the recognition framework in Southampton. The city has a dementia partnership that has variable attendance from a range of health and voluntary sector agencies. The regular attending agencies committed to delivering a number of pledges during 2015/16. The partnership lacks representations from social care, housing and other wider agencies.
9. There is desire within the partnership to extend the work into a formal framework that will enable delivery of a dementia friendly city in a more co-ordinated way, to include wider representation, and to consider appropriate resource.
10. The guests invited to present information at the meeting will take questions from the Panel relating to the evidence provided. Copies of any presentations will be made available to the Panel.

RESOURCE IMPLICATIONS

Capital/Revenue

11. N/A

Property/Other

12. N/A.

LEGAL IMPLICATIONS

Statutory power to undertake proposals in the report:

13. The duty to undertake overview and scrutiny is set out in Part 1A Section 9 of the Local Government Act 2000.

Other Legal Implications:

14. None

POLICY FRAMEWORK IMPLICATIONS

15. None

KEY DECISION? No

WARDS/COMMUNITIES AFFECTED:	None directly as a result of this report
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SUPPORTING DOCUMENTATION

Appendices

1.	Building dementia-friendly communities: A priority for everyone – Alzheimer's Society
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Documents In Members' Rooms

1.	None
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Equality Impact Assessment

Do the implications/subject of the report require an Equality Impact Assessment (EIA) to be carried out.	No
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Other Background Documents

Equality Impact Assessment and Other Background documents available for inspection at:

Title of Background Paper(s)	Relevant Paragraph of the Access to Information Procedure Rules / Schedule 12A allowing document to be Exempt/Confidential (if applicable)
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1.	None	
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Building dementia-friendly communities: A priority for everyone



Document purpose	<p>This report provides evidence on dementia-friendly communities from the perspective of people affected by dementia and their carers. It explores the barriers that people face in their community, how they would like to be engaged with their local area and the support they need to do so.</p> <p>It also collates existing evidence and describes projects that are already making a difference for people with dementia. This information is used both to provide a definition of a dementia-friendly community, and to lay out 10 areas of focus for communities working to become dementia friendly.</p>
Title	Building dementia-friendly communities: A priority for everyone
Publication date	August 2013
Target audiences	<p>Overall, the report aims to provide guidance to areas that are looking to become dementia friendly or to provide extra evidence for those already committed to becoming dementia friendly. It puts the views of people with dementia at the centre of the work, and offers relevant insights to central and local governments, the health and social care sector, wider public services, business and community stakeholders alike.</p>
Acknowledgements	<p>Alzheimer’s Society would like to thank all the people with dementia and their carers who responded to the survey, took part in interviews and shared their personal experiences. This report would not be possible without their contribution.</p> <p>Further thanks must go to all the Alzheimer’s Society staff, Dementia Action Alliance members and individuals and organisations who contributed their stories and provided invaluable case studies.</p> <p>We would especially like to thank the peer reviewers for this report: Dr Karim Saad, NHS England; Mr Matthew Hibberd, Local Government Association and Lucille Thirlby, UNISON.</p>
Authors	Geraldine Green, Senior Policy Officer and Louise Lakey, Policy Manager, Alzheimer’s Society
Contact	Alzheimer’s Society’s Public Policy team can be contacted on 020 7423 3500 or at ppa@alzheimers.org.uk
Web	alzheimers.org.uk/dementiafriendlycommunities
Publisher	© Alzheimer’s Society 2013. All rights reserved. No part of this work may be reproduced, downloaded, transmitted or stored in any medium without the written permission of the publisher, except for personal or educational use. Commercial use is prohibited.

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Foreword



It is an all too familiar story that people with dementia and their carers feel isolated or cut off from their local community. Think of the difference it would make to every person with dementia if they felt welcomed and empowered to get involved with activities and continue to participate in daily life. Sadly, the truth at the moment is that many people feel unable to join in, demonstrate their skills and make a real contribution to society.

Building dementia-friendly communities: A priority for everyone shows that people with dementia can face significant barriers to engaging in the social life of their area. Many find their local communities don't offer support or understanding for their condition, and so give up things they love to do out of anxiety or fear. Others lack confidence or feel they have nothing to contribute and no one tries to convince them otherwise.

All too often we hear that when people with dementia do find the courage to reach out, they are met with little or no response. If we are going to make an impact, remove stigma and enable people with dementia to be part of their communities then it's vital that we all play a part. A few small adjustments can help communities to become dementia friendly. We need individuals, organisations, and yes, whole communities to gear up and face the challenge.

I've been inspired by so many people, groups and organisations all over the country who are already working together to make a real difference. We've seen schools introducing dementia into the curriculum. It's fantastic to see the next generation thinking positively about how the condition affects people, and discovering for themselves how they can be supportive. Easy access to transport is essential for people with dementia who want to maintain their independence. So it is great to hear about the bus company determined to make a big difference for people with dementia and their carers by giving their drivers the opportunity to learn about dementia and ways in which they can help provide practical support to make travel easier.

At the other end of the scale, local businesses like a pie shop in Yorkshire have been playing their part. They've created a sales space away from the main till area where people with dementia can feel calm, comfortable and in control. They also offer help with shopping, counting out change and ensure pies are put in bags clearly marked with the purchase date – so they don't forget when to eat them.

We all have a responsibility to spread the message that everyone can make a difference. This might mean making sure that someone is still welcomed at an activity group, place of worship or club, or that a helping hand is being offered to anyone who appears lost or frightened.

When my mother was diagnosed with frontotemporal dementia I wanted her to be able to lead a fulfilled life and remain at home for as long as possible. She attended a care centre and took part in activities and singing sessions. I took her to the cinema and on shopping trips and made sure she met friends regularly for lunch. With encouragement, she kept links with her local friends and neighbours. Making sure she lived well with dementia was a priority. Everyone with dementia deserves that chance.

Our communities are made up of people who share their skills, experience and enthusiasm with friends, neighbours and the wider social network. These communities include people with dementia.

We can ensure that people with dementia live well with the condition. We can create a dementia-friendly Britain where people with dementia and their carers feel confident, understood, respected and included in all areas of life.

That is our challenge. It's one I truly believe we can achieve through our dementia-friendly communities programme for all people with dementia.

A handwritten signature in black ink that reads "Angela Rippon". The signature is written in a cursive style and is underlined with a single horizontal stroke.

Angela Rippon, OBE
Alzheimer's Society Ambassador

Executive summary

Introduction

Across England, Wales and Northern Ireland close to half a million people with dementia are living in the community and a third of those are living on their own (Alzheimer's Society, 2013c; Miranda-Costillo, 2010). For many, the idea of living well and having a good quality of life is still a distant dream. But change is underway and across communities we are starting to see small changes that are building to make a real difference.

Towns, cities and villages across the country are now seeing what they need to do to become dementia friendly, recognising the need to act and change in order to better support people with dementia. From Preston to Plymouth, Newcastle to Norwich, communities are setting out on a journey to transform the experiences of people with dementia and their carers.

Alzheimer's Society has been at the forefront of the creation of dementia-friendly communities. Working with governments and others, such as fellow members of the Dementia Action Alliance, we are supporting communities who want to become dementia friendly.

In order for dementia-friendly communities to succeed, the views and opinions of people with dementia and their carers must be at the heart of any considerations or decisions. This report provides evidence of dementia-friendly communities from the perspective of people affected by dementia. It explores the barriers that people face in their community, how they would like to be engaged in their local area and the support they need to empower them to do so.

Overall, the report aims to provide guidance to areas that are looking to become dementia friendly and to provide extra evidence for those already committed to becoming dementia friendly.

The report collates new and existing evidence from people with dementia and their carers with examples of projects that are making a difference for people with dementia. It uses this information to develop a definition of a dementia-friendly community and lay out 10 areas of focus for communities working to become dementia friendly.

This report acts as a useful source for those involved in the development of essential frameworks, systems and further guidance on creating dementia-friendly communities. It puts the views of people with dementia at the centre of the work, and offers relevant insights to central and local governments, the health and social care sector, wider public services, business and community stakeholders alike.

Key findings and statistics

The report firstly explores new evidence from people with dementia: their experiences of living in their community and the changes that they would like to see in place. Findings summarised below include the results from Alzheimer's Society 'DFCsurvey', to which over 500 people with dementia responded, and the invaluable evidence provided in interviews with people with dementia and their carers. It also includes results from a poll of over 2,200 UK adults conducted by YouGov.

While there are some excellent examples of communities gearing up for dementia, many people with dementia do not feel supported and a part of their local area.

- Less than half of the respondents to the DFCsurvey think their area is geared up to help them live well with dementia (42%).
- Less than half feel a part of the community (47%). Results become considerably lower the more advanced the person's dementia is.
- People from seldom heard communities expressed complex issues around feeling part of their community. Stigma was particularly highlighted by people with dementia and carers.
- More than half of UK adults surveyed in the YouGov poll feel that the inclusion of people with dementia in the community is fairly bad or very bad (59%).
- Nearly three quarters (73%) of UK adults surveyed in the YouGov poll do not think that society is geared up to deal with dementia.

Many people with dementia are not able to take part in activities that they enjoyed before they developed the condition. Many feel constrained by the condition and are not confident to get out and engage in their area. There is more that the person with dementia would like to do but they need support to do so.

- 35% of people with dementia said that they only go out once a week or less and 10% said once a month or less.
- 9% of people with dementia said they had had to stop doing all of the things they used to do.
- People said that they had to give up activities such as getting out of the house (28%), shopping (23%), exercise (22%) and using transport (16%).
- Shopping was identified as the most common activity that people with dementia do in their local area (79%), followed by socialising (72%), eating out (69%) and leisure activities (55%) such as going to the park, library or cinema.
- 63% of people with dementia did not want to try new things, and the underlying issues of confidence, worry and fear must be overcome in a dementia-friendly community.

People with dementia currently feel that they can't or don't know how to contribute to their local community. There is an overriding sense of low expectations and low self-belief.

- Two thirds of people with dementia (66%) do not feel they can make a contribution to their community. Despite wanting to do more, people feel restricted by their condition or health and hold low expectations about being able to contribute.
- Some people with dementia feel they can contribute by being personable, such as offering company and good conversation or socialising with others (10%), by volunteering (8%), sharing their skills (6%) or being involved in groups (4%).

The YouGov poll of UK adults shows that there is significant goodwill in the community to help people with dementia live well and a positive perception of the concept of dementia-friendly communities. Communities can utilise the recognition from the general public about the positive contributions that becoming dementia friendly can bring.

- Only 3% of UK adults think that people with dementia don't have anything to offer their communities.
- 47% of people think that dementia-friendly areas would be nicer places for everyone to live.
- 33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- 74% of UK adults think supporting people with dementia to be part of the community would help to reduce stigma.
- 40% of UK adults said that everyone has a role to play in supporting people with dementia.

While people with dementia face barriers to engaging with their community, it is possible to make changes that can make their day-to-day lives much better.

- People face psychological and emotional barriers to being able to do more in their community, alongside physical issues. The most common barriers are:
 - a lack of confidence (69%)
 - being worried about becoming confused (68%)
 - being worried about getting lost (60%)
 - mobility issues (59%) and physical health issues (59%)
 - not wanting to be a burden to others (44%)
 - lack of appropriate transport (33%).
- The YouGov poll found that UK adults think that the barriers that people with dementia face are due to issues such as stigma or lack of understanding about dementia from the general public (65%), a lack of formal and informal support from others to carry out the activities they want to (57%) and a lack of appropriate activities for people with dementia to do (53%).

To help support them to live well in their local area, people with dementia and their carers want a range of support.

- One third of people (35%) would like more care, support and services to do things in the community, including more opportunities to participate and help to attend activities through a befriender.
- 14% of people wanted better or more transport.
- 10% wanted improved health – related either to their dementia or another condition.
- Many people also mentioned that information should be readily available to help people make decisions about their day-to-day lives and the activities they engage in.

What is a dementia-friendly community?

The report collates the new evidence, existing evidence and examples of work being undertaken to provide a definition of a dementia-friendly community. This definition gives the essence of what a dementia-friendly community is striving for, which is underpinned by 10 key areas of focus.

A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

To achieve this, communities working to become dementia friendly should focus on the following 10 key areas:

1 Involvement of people with dementia

Shape communities around the needs and aspirations of people living with dementia alongside the views of their carers. Each community will have its own diverse populations and focus must include understanding demographic variation, the needs of people with dementia from seldom heard communities, and the impact of the geography, eg rural versus urban locations.

2 Challenge stigma and build understanding

Work to break down the stigma of dementia, including in seldom heard communities, and increase awareness and understanding of dementia.

3 Accessible community activities

Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.

4 Acknowledge potential

Ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities. Build on the goodwill in the general public to make communities dementia friendly.

5 Ensure an early diagnosis

Ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.

6 Practical support to enable engagement in community life

Deliver a befriending service that includes practical support to ensure people with dementia can engage in community life as well as offering emotional support.

7 Community-based solutions

Support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive, high-quality care homes. Community-based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.

8 Consistent and reliable travel options

Ensure that people with dementia can be confident that transport will be consistent, reliable and responsive and respectful to their needs.

9 Easy-to-navigate environments

Ensure that the physical environment is accessible and easy to navigate for people with dementia.

10 Respectful and responsive businesses and services

Promote awareness of dementia in all shops, businesses and services so all staff demonstrate understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business.

Dementia-friendly communities



Making the economic case for dementia-friendly communities

The rationale for creating dementia-friendly communities comes from the voices and experiences of people living with and affected by the condition. It is about ensuring that people with dementia are empowered to live well, and exert choice and control in their lives. Importantly, it recognises the impact that dementia has on relationships and people's confidence to engage in daily tasks and activities. These all have a profound impact on a person's quality of life, affecting not only the individual but also their carers and loved ones. Dementia-friendly communities seek to address this. Improving the wellbeing of every individual with dementia is of paramount importance in this work.

It is also suggested that there is an economic case for creating dementia-friendly communities. When making an economic cost-benefit analysis, quality-of-life indicators are very difficult to quantify and measure. Yet, even in the early stages of developing dementia-friendly communities, there are clear economic benefits to be realised, particularly within health and social care. Supporting people to live independently and safely in their own homes will lead to less time needed in costly residential or hospital care.

A dementia-friendly community should be a place where there is increased awareness that dementia is a disease that touches the lives of many, and so requires community-based solutions. Greater awareness will, in turn, support better diagnosis rates and joined-up working by health and social care providers. A dementia-friendly community will be a place where people with dementia and their carers are given assistance at home earlier, reducing the risk of comorbidities or falls, fractures or urinary tract infections, and helping reduce stress and fatigue in their carers. This will mean that the person with dementia could require fewer hospitalisations and remain in their own home for longer.

To put it into figures, a year living in the community with dementia (excluding the initial memory services assessment) is estimated to cost £24,128. This includes the cost of an integrated health and social care package, together with respite, therapies and medication. A year in residential care costs an average of £35,424. Therefore, for every person who is able to live at home rather than in residential care there is a saving of £11,296 per year or £941 per month. Therefore, if just 5% of admissions to residential care were to be delayed for one year as a result of dementia-friendly communities, there would be a net saving of £55 million per annum across England, Wales and Northern Ireland.

For further details and the methodology behind these costs see sections 1.4.4, Making the case for dementia-friendly communities: the individual health and social care pathway, 6.2, Appropriate care and support, and Appendix A: Economic case (for an infographic).

1 Introduction

1.1 Purpose of the report

This report provides evidence on dementia-friendly communities in England, Wales and Northern Ireland.* From the perspective of people affected by dementia, it explores the barriers that people face in their community, how they would like to be engaged in their local area and the support they need to empower them to do so.

The term ‘community’, within this report, relates to the area in which people live, including the shops and cafes they visit, the places they enjoy for recreation or leisure and the wider public spaces that surround them. It can be described as the various interfaces and interactions that a person with dementia and their carers require in their locality in order to live well.

The report focuses on how well people with dementia are currently living in their communities. It also reveals key areas of focus for any community working to become dementia friendly. These areas are suggested by the evidence and are brought alive with case studies from a range of organisations and communities to demonstrate the good practice and innovative work that is underway. Overall, the report aims to put the needs and experiences of people with dementia at the heart of the agenda.

It is acknowledged that essential frameworks and systems, such as the recognition process for dementia-friendly communities, are being developed and further guidance will be required. While this report cannot answer all the questions currently being asked, it does put people with dementia at the centre of the work, and offer relevant insights to central and local governments, the health and social care sector, wider public services, business and community stakeholders alike; including:

- those who can take responsibility for dementia-friendly communities in England, Wales and Northern Ireland at local and national levels. For example, national administrations, local authorities and councils, community leaders, clinical commissioning groups, health and wellbeing boards and the voluntary sector.
- those organisations and communities already working to become dementia friendly. This report acts as a resource to further understand the needs of people with dementia and shares examples of good practice.
- those organisations and communities that are thinking about becoming dementia friendly. This report offers the perspective of people with dementia and hopes to provide the inspiration for more areas to commit to becoming dementia friendly.

* These are the nations in which Alzheimer’s Society provides services.

This report is published at a vital moment. We have started to see a change in the way that people think about dementia and how to improve the quality of life of people affected by the condition. At international level, the impact of dementia is being recognised as an urgent public health priority (Wilmo and Prince, 2010; World Health Organization and Alzheimer's Disease International, 2012; International Longevity Centre UK, 2011).

In the UK, governments are acutely aware of the impact of dementia and increasingly the focus is on the development of dementia-friendly or dementia-supportive communities. This work is progressing rapidly, with many organisations, villages, towns and cities already taking steps towards becoming or expressing an ambition to become dementia friendly.

There is emerging evidence of areas that are becoming dementia friendly through building awareness of dementia, empowering people living with the condition, and providing support for carers and families throughout its progression. Improved access to information on all aspects of the condition, from awareness following diagnosis to signposting for support, is crucial in a dementia-friendly community. Every aspect of this report is contingent on improved information. This includes access to health and social information, which is recognised but not addressed in this report.

Yet while there is an increasing groundswell to make communities more dementia friendly, the findings from this report show that much more needs to be done if we are to meet the challenge of dementia. Every person with dementia has the right to live well in their community and everyone, from governments and communities to businesses and individuals, has a role to play in making this a reality. It is now the time for action to improve the lives of people living with the condition.

1.2 Dementia-friendly communities: the context

There is now significant public and political commitment to action on dementia in England, Wales and Northern Ireland and the urgency of the situation has never been more apparent. Currently in the United Kingdom there are 800,000* people living with dementia and at least 17,000 of these people are aged under 65 (Alzheimer's Society, 2012a). Over 670,000 people are acting as primary carers for people living with dementia and the demands on individuals and families are set to increase (Alzheimer's Society, 2012a). Over the next 40 years the number of people living with dementia will double to 1.7 million (Alzheimer's Society, 2007).

Two thirds of people with dementia live in the community, and people with the condition occupy up to a quarter of hospital beds and up to 80% of places in care homes (Alzheimer's Society, 2007, Alzheimer's Society, 2013a). Delivering integrated and personalised care is essential for people to live well with dementia yet the health and social care system is buckling under the pressure. Dementia is costing the UK £23 billion a year and over a third of these costs are borne by informal care from family members and other unpaid carers (Alzheimer's Society, 2012b).

* This figure is calculated using consensus prevalence estimates from Alzheimer's Society Dementia UK report (2007) applied to Office of National Statistics population estimates.

It is clear that neither families nor the health and social care system can meet the demands of dementia alone. This report focuses less on the formal health and social care system and more on how community assets can be mobilised in support of dementia-friendly communities. We acknowledge, nevertheless, that care homes and hospitals play a vital role in supporting people with dementia and creating dementia-friendly communities. The movement to become dementia friendly therefore seeks to address the full range of issues that affect quality of life.

There has been much research on the quality-of-life outcomes that are important to people with dementia. For example, the National Dementia Declaration for England (Dementia Action Alliance, 2010) captured seven outcomes, as described by people with dementia and carers, that are needed to live well with the condition. These are:

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

Realising the work that needed to be done to make these outcomes a reality for people with dementia, in 2012 Alzheimer's Society campaigned for dementia to be recognised as a challenge for society (Alzheimer's Society, 2012a). Alzheimer's Society and its partners in the Dementia Action Alliance are now committed to delivering a social movement, where organisations and communities work to change the way society views and supports people with dementia (see Appendix B for list of Dementia Action Alliance members).

While there are many initiatives being progressed under the agenda of age-friendly communities (World Health Organization, 2007) this report calls for people with dementia to be at the heart of discussions. When you get it right for people with dementia, care and community life will be more inclusive for a much wider range of people.

Political leaders have now taken crucial steps towards addressing this challenge and acknowledge that solutions must be based around the person and all of the factors that influence how they live. The Dementia Friendly Communities programme in England and Northern Ireland and the dementia-supportive communities programme in Wales seek to address these issues by working with and empowering people with dementia to live well.

1.3 Mobilising support for dementia-friendly communities

Creating dementia-friendly communities must be part of a social movement to help people live well with dementia. Both sustained national leadership and grassroots action on dementia are required to create a dementia-friendly Britain. The Prime Minister's challenge on dementia in England acknowledged that the dementia challenge will not be met by health and social care alone.

There is untapped potential in the community to help people with dementia and their carers. Everyone, from governments and health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel active, engaged and valued in their local area. Areas already taking action have recognised some of the many ways to bring people together and rally to the cause of becoming dementia friendly.

There are many starting points for communities who want to become dementia friendly. For example, in Debenham, members of the local church pulled together a broader community meeting because of their concerns about caring for people with dementia. In the village of Idle, the local Alzheimer's Society working with the council's Neighbourhood Service and District Care Trust joined with committed individuals to bring together a small action group to look at what was working and what more could be done to become dementia friendly. In York, the Dementia Without Walls action research project, run by the Joseph Rowntree Foundation, involved people with dementia and their carers from the beginning to see how York could be a better place for people with dementia. The baton has now been taken up by the City of York Council to make this a reality.

Central to all of these approaches has been pulling together a network or action group of interested parties that are personally committed to making a difference for people affected by dementia. Collaboration with local partners is essential; this can include the health and care sector, voluntary organisations and local businesses for example. Support from local political leaders has also proven valuable to many of the projects.

There are now 35 Dementia Action Alliances working on action plans to transform the quality of life for people living with dementia. These local alliances or similar action groups bring together diverse stakeholders including bus companies, taxi firms, police, fire and rescue services, high streets, local authorities, charities, care providers and health trusts, faith groups and schools.

Communities are invited to sign up to the recognition process for dementia-friendly communities. The recognition process enables communities to be part of an officially recognised group working towards becoming dementia friendly. It ensures that all communities are working towards common, evidence-based criteria that will truly change the things that matter to people affected by dementia. Through these criteria, people with dementia, no matter where they live or travel to, will be able to recognise areas that are dementia friendly and know what they can expect.

Communities must commit to working towards particular criteria, including having a local dementia action alliance or similar group in place. This report aims to provide extra guidance on which key areas to address within a dementia-friendly community by sharing the experiences and evidence from people with dementia.

Some communities are well advanced on the dementia-friendly journey. York, Crawley, Bradford, Debenham, Camelford, Plymouth, Doncaster, Thurrock, Tavistock, Falmouth, Hampshire, Sheffield, Surrey and Leeds were early adopters in the pilot recognition process, leading the way and sharing experiences. Learnings from these communities have been invaluable and some of their examples and projects are highlighted in this report.

1.4 Methodology

This report draws together a wide variety of evidence.

1.4.1 The experiences of people with dementia and carers

Alzheimer's Society staff and other networks distributed a survey to people with dementia in October and November 2012. For clarity, this survey is called the 'DFCsurvey' throughout the report.

Of the 510 responses:

- 17% of responses were filled in by the person with dementia on their own, 46% with a family member, friend or carer, 31% on behalf of the person with dementia, and 4% with a health and social care professional
- 16% of respondents lived on their own, 65% with a carer, 5% with someone who is not their carer, and 7% in a care home
- 8% of respondents were under 65 years, 28% were aged between 65 and 74, 43% were aged 75–84, and 21% were over 85.
- 4% had been experiencing the symptoms of dementia for under 1 year, 45% between 1 and 3 years, 31% between 4 and 6 years, 13% between 7 and 9 years, and 7% for over 10 years.

There was a very strong response from England (93%) and representative response rate from Wales (5%). 1% of the respondents were from Northern Ireland. An additional interview was held with a person with dementia living in Northern Ireland to inform the report.

It is acknowledged that most of the respondents had obtained a diagnosis and have been or are in contact with Alzheimer's Society services or other support services. This represents the minority of people living with dementia in England, Wales and Northern Ireland. In the UK, 54% of people with dementia are yet to receive a diagnosis and it is anticipated that those people's experiences of community life are diverse and difficult (Alzheimer's Society, 2013c). However, the views of people who responded the DFCsurvey and interviews provide us with a valuable picture of what living in the community is like and the barriers they face to being able to do more.

1.4.2 Seldom heard groups

Alzheimer's Society acknowledges the importance of ensuring that all people with dementia, irrespective of their diagnosis, gender, age, ethnicity or religion for example, are empowered to contribute to the work on developing dementia-friendly communities. Recent evidence suggests that there are nearly 25,000 people with dementia from black, Asian and minority ethnic communities in England and Wales and that there will be huge growth in the number of people with dementia from these communities (All-Party Parliamentary Group on Dementia, 2013).

Of those responding to the DFCsurvey, 96% identified themselves as white and 2% as black/African/Caribbean/black British. To explore a wider range of views and understandings of dementia-friendly communities, focus groups and interviews were held with over 20 people from seldom heard communities – including people from rural, South Asian and white Irish communities, one younger person with dementia and a gay carer.

While the evidence gathered in these interviews provides a small glimpse into the issues that people with dementia and their carers face, it is, however, an important contribution to the relatively scarce evidence base on people with dementia from seldom heard communities. Further research is needed to understand how services and communities can be more inclusive and accessible to all people with dementia. This should also include people from traveller communities, people with learning difficulties and lesbian, gay, bisexual and transgender people.

1.4.3 The views of the general public

Alzheimer's Society commissioned a YouGov poll of 2,287 UK adults to uncover what the general public thinks about people living with dementia in their community. The figures were weighted to be representative of all UK adults aged 18+. The survey was conducted online in January 2013.

1.4.4 Making the case for dementia-friendly communities: the individual health and social care pathway

Alzheimer's Society commissioned Crystal Blue Consulting, an experienced economic and financial consultancy, to consider how a dementia-friendly community could affect health and social care costs at the individual level. Looking across current demographics, the potential economic impact of dementia-friendly communities was considered according to each element of the care pathway. This included costs associated with the initial presentation, diagnosis, case management through to actions in the home, residential and hospital care setting.

The overall case is outlined in the Executive summary (page v) and an infographic of the cost pathway can be found in Appendix A: Economic case.

1.4.5 Existing research and good practice

Alzheimer's Society consulted with a range of existing research and examples of good practice, including the following:

- Existing academic sources and research from think tanks, such as the Joseph Rowntree Foundation and the Social Care Institute for Excellence were consulted.
- Practical examples of projects, organisations and communities that are setting out to become dementia friendly have been incorporated and, wherever possible, direct quotes and case studies from people with dementia have been used.
- Local Alzheimer's Society services and other not-for-profit or community-based services and providers also provided important advice to the report.
- Members from national and local Dementia Action Alliances and the dementia-friendly communities champion group also shared their work.

2 What does the evidence tell us about how well people are currently living in their area?

Summary

This section highlights that, while there are some excellent examples of communities gearing up for dementia, many people with dementia do not feel supported and a part of their local area.

- Less than half of the respondents to the DFCsurvey think their area is geared up to help them live well with dementia (42%).
- Less than half feel a part of the community (47%). Results become considerably lower the more advanced the person's dementia is.
- People from seldom heard communities expressed complex issues around feeling part of their community. Stigma was particularly highlighted by people with dementia and carers.
- More than half (59%) of UK adults feel that the inclusion of people with dementia in the community is fairly bad or very bad.
- Nearly three quarters (73%) of UK adults surveyed in the YouGov poll do not think that society is geared up to deal with dementia.

A dementia-friendly community must:

- be shaped on the needs and aspirations of people living with dementia and their carers. Each community will have its own diverse populations and focus must be on understanding the demographic variation, the needs of people with dementia from seldom heard communities and the impact of geography.
- focus on increasing public understanding of dementia and dispelling misinformation and myths about the condition.

2.1 Are communities geared up to help people live well with dementia?

The National Dementia Declaration for England (2010) identifies that people with dementia want to live in communities that give them choice and control over their lives and provide services and support designed around their needs. Importantly, they want to feel valued, understood and part of family, community and civic life.

There is also a growing recognition of the need to consider the impacts of social relationships, networks and community involvement. These factors influence whether people feel part of their community and have been shown to contribute to better health and quality-of-life outcomes for all (Alzheimer's Society, 2011; Windle et al 2011; Miranda-Castillo et al, 2010).

However, findings for this report suggest that people with dementia do not always feel supported and a part of their local area and that the general public also feels that society is not geared up for dementia:

- Less than half of the respondents to the DFCsurvey think their area is geared up to help them live well with dementia (42%).
- Less than half feel a part of the community (47%).
- 73% of UK adults surveyed in the YouGov poll do not think that society is geared up to deal with dementia.
- 59% of UK adults feel that the inclusion of people with dementia in the community is fairly bad or very bad.
- 60% do not believe that the government has responded well to the challenge of dementia and more than half of people feel that those living with dementia experience a poor quality of life (Alzheimer's Society, 2013a).

Despite public awareness campaigns and political attention on dementia, overall understanding of the condition also remains low:

- 49% of UK adults surveyed as part of the YouGov poll think that public understanding of dementia is fairly bad or very bad.
- At the individual level, less than half (48%) of people think they personally have a good understanding of dementia.

The findings suggest that support, care and understanding in the community are often falling short of the needs and aspirations of many people with dementia. Within this context, greater support is urgently needed for carers. A survey of more than 2,100 carers, of which 17% of respondents cared for a person with dementia, found that 75% of carers were not prepared for all aspects of caring. Nor were they prepared for the emotional impact, lifestyle or relationship changes of their caring role (Carers Week, 2013). Failure to prepare and support carers in their role not only affects their own personal health and wellbeing, but can also lead to the early and potentially avoidable admission of people with dementia into formal care.

Other research shows that people with dementia feel socially isolated and lonely (Innovations in Dementia, 2011; Alzheimer's Society, 2013a), face difficulties in completing everyday community activities often taken for granted by others (Crampton et al, 2012) and feel worried about being able to cope in communities that don't understand dementia (Local Government Association and Innovations in Dementia, 2012). This contrasts with 78% of people aged over 65 who say they are satisfied with feeling part of their community (Age UK, 2013).

Interviews with people from seldom heard groups also highlighted that the community is not geared up for individuals with dementia.

People from seldom heard communities expressed a number of complex issues around feeling part of their community. Some issues such as stigma were particularly highlighted:

'I think that generally, most people from Asian families, they try to sort of play it down, they don't want people to know that they have got people with problems, like dementia... they think you're like a person being mad or something. It's a stigma. [Dementia] is not easily understood by the community.'

There is quite a large community but they just disappear... We have no word for dementia in our culture, people think you're mad or normal, there is no in between... There is a lot of stigma attached to the condition and I think it's a topic people don't talk about very openly.

I don't know anybody else who has this and if they have it, I don't know about it. I cannot believe that there is not one other person that somebody somewhere knows within the circle of friends that my parents have [in the Bangladeshi community].'

Comments from interviews with people from seldom heard groups

The All-Party Parliamentary Group report (2013) on dementia in black, Asian and minority ethnic communities found that people from BAME communities tend to face higher levels of stigma and are at risk of being isolated as social networks drift away. These communities may also face taboos about dementia and assumptions about care that isolate people further, such as a 'look after their own' stereotype.

Case study

A is an Irish born woman who was the main carer for her late husband who had dementia. Although A found that some people in her community understood dementia, there were still a lot who didn't want to acknowledge it. While her family were supportive, some friends just didn't want to know and they avoided meeting them. Overall, A feels that unless people have experienced it for themselves there is a general lack of interest in dementia.

However, it is important to acknowledge that there are some excellent services and initiatives in place. The evidence for this report highlights many examples where communities are starting to get it right for people with dementia. For example, common themes include neighbours, friends and family demonstrating understanding and being helpful, people 'not making a fuss' about the individual's dementia, and having the right support and services on hand.

'People probably have made comments [about my dementia]. But they don't upset me. In our village, everyone's fine. We have a lot of friends [who] rally round and bother to be in touch. It's a big muddle isn't it!'

'Excellent support in [town]. People don't gawp, don't make a fuss about it. And you can see that they know, from their body language. The pub... are brilliant, normal and helpful and the tea shop...make us feel welcome.'

Interview comments from people with dementia from rural areas

Areas that have started on the path to becoming dementia friendly identify similar themes as important to people with dementia. People with dementia described the importance of living in safe and accessible environments, having helpful staff in shops, access to support services, activities to attend and strong networks of friends, family and neighbours (Innovations in Dementia, 2011).

Case study

B and her husband live in Wales. B's husband has Alzheimer's disease.

'When [my husband] was first diagnosed with Alzheimer's I visited our local shops in Cardiff to explain the situation and gave them my contact details. Many of the shopkeepers had known [my husband] for years, so they'd know if something was amiss and could telephone me. On one occasion, [my husband] had a dentist appointment. I had nipped into a shop to buy a newspaper, while he walked ahead. When I arrived at the dentist he wasn't there. I hurried to look for him, and when I returned I found that the dentist herself had gone looking in the other direction and found him. Kindness like that is so heartening and it was reassuring for me to know that the local community was so understanding and supportive.'

2.1.1 Differences between rural and urban communities

The results of the DFCsurvey show some interesting differences when broken down according to geographical location. Tables 1 and 2 identify the differences in whether people feel that their local area is geared up to deal with dementia and whether people feel part of their community according to where they live. 'Countryside' has been included for people who identify as not living in a village.

Table 1: How well people feel their local areas are geared up to deal with dementia

DFCsurvey: Do you think your local area is geared up to help you live well with dementia?			
Location	Yes (%)	No (%)	Don't know (%)
Overall	42	26	32
City	31	27	42
Town	50	23	28
Village	38	28	34
Countryside	28	22	50

Table 2: Inclusion of people with dementia in the community

DFCsurvey: Do you feel part of your community?			
Location	Yes (%)	No (%)	Don't know (%)
Overall	47	35	18
City	51	32	17
Town	44	34	21
Village	53	3	11
Countryside	37	32	32

People living in towns or villages are more likely to think that their local area is geared up to help them live well with dementia than people living in the countryside or cities. Further, people living in villages are more likely to feel part of their community, along with people living in cities, than those in towns or the countryside. While these results are from a small number of respondents, they do highlight the variation that can occur across different geographical settings.

Research conducted by Innovations in Dementia (2011) looked into what a dementia-capable community looks like across three settings: rural, small town and urban. While there were some generally consistent findings across the different settings relating to comments about the physical environment, local facilities, support services, social networks and local groups, there were also different priorities attached according to location. A study of people living with dementia in the area North of Tyne (Clarke et al, 2012) also highlighted the significance of place, finding for example that people from rural areas identify a strong sense of feeling part of their community but may be less inclined to ask for help from health services when needed.

Where people live, the infrastructure and resources around them will affect the needs of people with dementia and their carers. A dementia-friendly community must therefore be based on the experiences of people living with dementia in that area.

2.1.2 Number of years of experiencing dementia

Tables 3 and 4 show whether people with dementia feel part of their community and whether they feel their local area is geared up to deal with dementia. These results also indicate how the length of a time a person has been experiencing dementia affects their response to these questions.

Table 3: Feelings of inclusion of people with dementia according to the length of experience of dementia symptoms

DFCsurvey: Do you feel part of your community?			
Length experience symptoms of dementia (years)	Yes (%)	No (%)	Don't know (%)
Less than 1	73	13	13
1-3	53	32	15
4-6	43	36	21
7-9	37	42	21
10+	31	46	23

Table 4: How well people feel their local areas are geared up to deal with dementia according to length of experience of dementia symptoms

DFCsurvey: Do you think your local area is geared up to help you live well with dementia?

Length experience symptoms of dementia (years)	Yes (%)	No (%)	Don't know (%)
Less than 1	69	13	19
1-3	44	20	35
4-6	42	27	31
7-9	32	40	28
10+	39	36	25

Those who have been experiencing the symptoms of dementia for a shorter time are more likely to think their local area is geared up to help them live well with dementia, and feel more a part of their community, than those that have had dementia for longer.

This will in part be explained by the progression of dementia, but this alone cannot justify the range of difference between the findings. At any stage of dementia, people are entitled to care and support that maintains their quality of life. People at all stages of the condition need to be engaged and involved in research to ensure that their views are brought to bear.

3 How active are people with dementia in their local area?

Summary

This section explores how active people with dementia are. It finds that many people with dementia are not able to take part in activities that they enjoyed before they developed the condition. Many feel constrained by the condition and are not confident to get out and engage in their areas.

- 35% of people with dementia said that they only go out once a week or less and 10% said once a month or less.
- Shopping (79%) was identified as the most common activity that people with dementia do in their local area, followed by socialising (72%), eating out (69%), and leisure activities (55%) such as going to the park, library or cinema.
- 9% of people with dementia said they had had to stop doing all of the things they used to do.
- People said that they had to give up activities such as getting out of the house (28%), shopping (23%), exercise (22%) and using transport (16%).
- Many people with dementia feel constrained by the condition and are not confident to get out and engage in their local areas. Overwhelmingly, 63% of people with dementia did not want to try new things.

A dementia-friendly community must:

- have more activities geared towards people with dementia and ensure that existing leisure services and entertainment activities are more inclusive of people with dementia; planning must centre on the needs, interests and motivations of people with dementia in their local area
- ensure that people in the community have access to an early diagnosis and post-diagnostic support; this will allow for early planning and the introduction of strategies and adaptations to help people maintain their interests and continue engaging in activities in a way that is meaningful to them
- overcome any underlying issues of confidence, worry and fear that discourage people with dementia from trying new ways of taking part in their community.

3.1 How often do people with dementia go out in their local area?

The DFCsurvey shows that nearly half of people with dementia go out to do things in their local area every day. Of the respondents 35% only go out once a week or less and 10% only go out once a month or less.

On a weekly basis, people with dementia appear to go out significantly less than the general population of people aged over 65 (Age UK, 2013). While there will always be individual preferences as to how much people want to go out, there was an overriding sense in the evidence gathered for this report that people wanted to do more but felt restricted from being able to do so.

For example, many described their dependency on others to enable them to do activities or engage in their community. Dementia 2013 (Alzheimer's Society 2013a) found that 88% of people with dementia rely on family and friends to take them out for activities in the community. Others responded that they walk to activities. Indeed, research has found that as their dementia progresses, people will tend more towards activities that are less demanding and within walking distance of their home (Burton, Mitchell and Raman, 2004). The progression of dementia, availability of activities and support to attend may also affect the frequency with which people are able to get out in their area.

The benefits of getting out and engaging with others are well documented. Duggan et al (2008) for instance, found that continuing outdoor activity for people with dementia may lengthen the period of high-quality living, while reducing how long people need to use intensive services. Researchers involved in the Inclusive Design for Getting Outdoors (2013) consortium also highlight the importance of accessible outdoor spaces for older people to help avoid people feeling 'trapped' in their own homes.

Ensuring that the outside environment is accessible has substantial potential for improving quality of life by ensuring people have opportunities for social interaction, promoting a sense of community and enjoying variety and purpose in their daily activities.

3.2 What do people do in their local area?

The DFCsurvey asked what people with dementia do in their local area. This was a fixed choice question and respondents were asked to answer whether they participated in each of the listed activities. The results are shown in Table 5.

Table 5: Activities that people with dementia participate in

DFCsurvey: If you do go out in your local area, what sort of things do you do?			
Activities	Yes (%)	No (%)	Don't know (%)
Shopping	79	20	1
Errands, for example banking, visiting post office	46	52	
Socialising	72	23	4
Leisure, for example visiting a park, library or cinema	55	42	2
Eating out	69	30	1
Going to a religious service	30	68	7

Shopping was identified as the most common activity that people with dementia do in their local area, followed by socialising (72%), eating out (69%), and leisure activities (55%) such as going to the park, library or cinema.

The interviews with people from seldom heard groups also explored the type of activities they participate in. Responses included faith services, peer support and other dementia services:

‘The reminiscing [group] once a month – he enjoys that and there are men as well as women which is nice for him. Pensioners’ meeting with me, church and the allotment either on his own or together, the lunch club sometimes.’

‘We both enjoyed the reminiscence group that we went to before Christmas and will continue with that. Apart from that her interest is really her family and her faith.’

People with dementia and their carers interviewed from seldom heard groups

This question was also met less positively, with some not knowing how to answer the question, and others revealing a sense of hopelessness about what sort of things they could do:

‘Nothing, he keeps repeating himself and roaming around the flat – he can’t settle to anything.’

‘I really don’t know as she can spend ages staring into space – once or twice in the group she did take an interest talking about work and said a few things and when trying on hats – me not her – she laughed and I hadn’t heard her do that in some time.’

‘Very few – excess energy so he needed to walk and get plenty of exercise – he would disappear with the dog for hours and arrive back to my relief. He could not concentrate on reading, TV or games. Music, especially the music he remembered from home.’

People with dementia and their carers interviewed from seldom heard groups

While acknowledging that interests and motivations will change over time, people with dementia have expressed their wish to continue doing the activities that they used to prior to their diagnosis (Öhman and Nygård in Brorsson et al, 2011). Many of the activities described by people with dementia included the day-to-day tasks that contribute to people’s sense of independence and purpose. As the next section will explore, people with dementia are not always able to do this and have had to give up activities and stop going out in their local area.

3.3 What have people with dementia stopped doing in their local area?

The DFCsurvey sought to identify whether people have had to stop doing activities that they used to do. Respondents were asked an open-ended question and some responses involved more than one of the categories identified.

Table 6 identifies these responses and reveals that people with dementia have had to stop doing many of the things they used to do. While a few people mentioned that they lived full lives, 9% said they had had to give everything up.

In addition, people said that they had to give up activities such as getting out of the house (28%), shopping (23%), exercise (22%) and using transport (16%). The exercise activities that people particularly mentioned as having to give up included walking, golf, dancing and gardening.

Table 6: Activities that people with dementia have stopped

DFCSurvey: Are there things that you used to do but have stopped doing?	
Activity	Stopped or reduced attendance (%)
Everything	9
Shopping	23
Going to library/reading	11
Group activities	8
Eating out	8
Exercise	22
Religious services	3
Transport	16
Getting out of the house	28
N/A	8
No	9
Don't know	1

Many of those interviewed from seldom heard communities noted the increasing difficulty of finding activities to do or continuing to do activities as their dementia progressed. Religious activities and day-to-day tasks, such as driving, shopping and cooking, were mentioned

‘Going to the hairdresser, pottering around charity shops on my own.’

‘Many things my husband cannot do. Walking is very difficult, and reading is almost impossible. He enjoys live music, especially children singing (he was head of a large primary school).’

‘Visiting the yacht club where most social visits happened. Some people began to shy away.’

‘My shopping is almost non-existent and only possible when accompanied by a member of my family. I can walk only a few yards unaided. This limits my going out.’

Survey and interview respondents with dementia and their carers

3.4 New activities that people with dementia would like to try in their local area

The DFCsurvey asked respondents about the activities they would like to try in their local area. Both positive and negative responses were recorded for this question. Some respondents included more than one activity and answers have been grouped with the statistics summarised in Table 7.

Table 7: Activities that people with dementia would like to be involved in

DFCsurvey: Are there things that you would like to be able to do in your area? For example things you used to do or things you have never tried, such as visiting the library or playing sport?	
Response	(%)
Any variation on 'no'	63
Not possible because of condition	12
Not possible because of transport/mobility	7
Not possible because of age	3
Not possible because activity not available	6
Other 'no' mentions	35
Don't know	5
Sport	12
Music	2
Religious service	1
Other hobbies	19
Still do everything used to do	7
Independence lost	1

As shown in Table 7, the DFCsurvey found that many people with dementia feel constrained by the condition and are not confident to get out and engage in their areas. Overwhelmingly, 63% of people with dementia did not want to try new things and the underlying issues of confidence, worry and fear must be overcome in a dementia-friendly community.

In answering this question, 7% of respondents felt they were still doing all the things they would like to do while the majority, 63% of people, did not wish to try new things in their community and a further 5% did not know how to answer the question. Top reasons for not wanting to try new things were:

- having dementia (12% of all answers)
- transport and mobility issues (7%)
- activities not being available (6%)
- their age (3%).

People with dementia were very clear on identifying that they need more information on what social activities and opportunities are available, that more activities need to be available and support is required to attend any opportunities.

‘More social activities for people with memory loss and dementia where people understand and support you – not institutional day care – arts and crafts, quizzes, music or just opportunities to meet people and socialise.’

‘I would like to but they are not geared up to accommodate people with my mental and physical needs.’

‘Because I am in a nursing home activities are very limited. I rely on family to enable me to do certain activities for an hour or two almost every day one of which is the monthly Alzheimer meetings for a singalong, which I enjoy very much.’

Respondents to the DFCSurvey

There were a small number of responses where people described how they are still able to do things either as before or in a modified way. These answers show the potential for people to maintain activities, if they are modified in a way to suit the individual’s capacity to contribute.

‘I am always willing to give new things a try and join in with a variety of the activities and events at the extra care scheme I live in. I will watch if I can’t join in, and help when I can.’

‘I carry on as before aware that my memory is not brilliant and I need to write more things down.’

‘Still do everything, but less.’

‘We carry on almost as usual with the help of our local Alzheimer “Drop In” centre.’

‘There are special activities arranged by the care home where I live.’

Respondents to the DFCSurvey

Findings from other research draw similar conclusions about the type of things people would like to try in their area, most commonly grouped around the four categories of: pursuing hobbies and interests; going out more; using local facilities; and volunteering opportunities (Innovations in Dementia, 2011). As noted in the previous section, like all people, the motivation of people with dementia will change over time and it is important to find activities that meet the person's needs and interests. Some research has noted a preference for one-to-one activities as joining groups can be intimidating for people with dementia (National Development Team for Inclusion, 2013).

However, throughout the research there is a sense of fear and worry about how dementia constrains people's ability to continue in meaningful activities. Within this survey, 12% of people made an explicit reference to dementia acting as a limitation to engaging in new activities. This appears to be a typical experience of people with dementia, with many describing their fear or worry at the lack of understanding from others and the difficulties that dementia presents. For some there is an overall sense of having to 'give up' after a diagnosis (Innovations in Dementia, 2011; Joseph Rowntree Foundation, 2012).

Crampton et al (2012) reported that some of the people with dementia they interviewed felt that their choices and aspirations had become constrained as they become known as 'one kind of person (ie a person with dementia)'. People may be discriminated against on the basis of their dementia and this can have lasting negative effects on people's self-confidence to re-engage. An Age UK service (which provided evidence for the report) described an example of a couple being told they couldn't attend a local history group because the person with dementia may not understand the fire alarm and posed a risk to health and safety.

Engaging in activities is an important aspect of wellbeing. NICE guidelines (2013) recognise that taking part in meaningful leisure activities is important for people with dementia and can help improve quality of life. However, as a person's dementia progresses, there is likely to be an impact on the type of activities that they can participate in and their willingness to try new activities that are less familiar. People with dementia will need increasing support to continue to engage in activities, owing to many factors relating to their condition and the barriers they face in the community.

While more activities are needed for people with dementia, there is also significant scope for existing leisure services and entertainment activities to be more inclusive of people with dementia. Planning must centre on the needs, interests and motivations of people with dementia in their local area.

Early planning is also needed to ensure that people are equipped to handle the changes that dementia will place upon them as the condition progresses. For instance, there are particular issues when people are forced to give up activities with little notice or planning. Being told to give up driving abruptly, for example, can be particularly difficult for older people, as it not only provides a means for community engagement, especially in rural areas, but also because driving is associated with feelings of independence and freedom (Musselwhite, 2011).

Early planning can only occur when people are given a timely diagnosis. Most people, however, only receive a diagnosis after their relationships, cognition and quality of life have been significantly challenged (Brooker et al, 2013). A diagnosis later on in the progression of dementia means that people will have missed out on vital support that could have kept them engaged and living well for longer. It is essential that people are diagnosed early on to ensure that they make decisions about their care while they have capacity to do so.

An early diagnosis must be followed by post-diagnostic support that offers counselling and coping strategies and ensures a positive adjustment to living with the condition. There are strategies and adaptations that can be introduced to help people maintain their interests and continue engaging in activities in a way that is meaningful to them. These are essential components in a dementia-friendly community.

4 What would people with dementia like to contribute to their local area?

Summary

This section reveals that people with dementia currently feel that they can't or don't know how to contribute to their local community. There is an overriding sense that they have low expectations and lack the belief in themselves to be able to do more.

- Two thirds of people with dementia (66%) do not feel they can make a contribution to their community. Despite wanting to do more, people feel restricted by their condition or health and hold low expectations about being able to contribute.
- Some people with dementia feel they can contribute by being personable, such as offering company and good conversation or socialising with others (10%); by volunteering (8%), sharing their skills (6%) or being involved in groups (4%).
- Only 3% of UK adults think that people with dementia don't have anything to offer their communities.
- 40% of UK adults said that everyone has a role to play in supporting people with dementia.

The YouGov poll also revealed:

- 47% of people think that dementia-friendly areas would be nicer places for everyone to live.
- 33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- 74% of UK adults think supporting people with dementia to be part of the community would help to reduce stigma.

Summary

A dementia-friendly community is a place where people living with the condition are able to share their company, experiences and skills with others.

- It is critical that people with dementia themselves acknowledge that people living with the condition can continue to make a positive contribution to their communities.
- This empowerment can come about by engaging those living with the condition in the design of dementia-friendly communities.
- Communities should also utilise the recognition from the general public about the positive contributions that becoming dementia friendly can bring. Across the UK, there are committed individuals who recognise they have a role to play in supporting people with dementia. Part of becoming a dementia-friendly community involves mobilising this support into action.

4.1 The contribution that people with dementia can make to their community

People with dementia and their carers were asked what contribution they think they can make to their community, for example volunteering and sharing skills. Answers were then grouped to provide a statistical breakdown of the most common responses. Some answers involved more than one activity and have been coded accordingly.

As Table 8 shows, the most popular answers from people with dementia as to the contribution they could make in their community included:

- activities around being personable, such as offering company and good conversation or socialising with others (10%)
- the potential to share skills with people, including crafts, training or languages (6%)
- volunteering (8%)
- being involved in groups (4%)
- helping at religious services (3%)
- performing or engaging in music activities (3%).

Table 8: The contribution of people with dementia

DFCSurvey: What contribution do you think you can make to the community? For example volunteering, sharing skills	
Response	(%)
Any mention of no contribution	66
Not possible because of condition or health	15
Not applicable	4
Won't because isn't that kind of person	1
Other reason for answering no	47
Don't know	6
Being personable	10
Sharing skills	6
Attending/helping at religious service	3
Volunteering	8
Music	3
Involved in groups or leisure activities	4

However, 66% of people with dementia responding to the DFCSurvey did not feel that they could contribute to their community and a further 6% answered 'don't' know' to the question.

It must be acknowledged that some people with dementia will not want to or be able to contribute to their community. However, the large numbers of people responding that they cannot make a contribution can also be explained by the finding that respondents have low expectations as to their ability to contribute to their community.

There was a strong sense from respondents of not knowing how or what they could do to contribute. The responses below begin to demonstrate how people feel:

‘I don’t know. I don’t feel that I have much to offer now because of my memory problems.’

‘Nothing to contribute due to mental health and lack of confidence.’

‘Regrettably, none. I have Alzheimer’s which is slowly worsening from loss of memory in the late afternoon/evenings to early in the day.’

Respondents to the DFCSurvey

Some respondents actively used the question to seek help or guidance on what contribution they could make and others described their potential contribution:

‘Please tell us we would love to fill a day in a more useful or constructive way! But lack of mobility – plus no longer able to read or write – makes this very difficult.’

‘If you specified what is required or what is available I could assess my abilities.’

‘I think I could volunteer for things helping others and sharing skills that I can remember.’

‘Loving. Leafleting in making others aware of Alzheimer’s. Walking the elderly infirm dogs. With my husband helping to do minor tasks and repairs etc.’

Respondents to the DFCSurvey

Respondents also shared ways in which they are currently contributing, and responses show the range of skills that could be encouraged and promoted in a dementia-friendly community.

‘I cannot make a direct contribution to the wide community but I do “give of myself” in my “Care Home Community” by taking part in many activities and the residents’ council meetings. Although my short-term memory is very limited (15 to 20 minutes sometimes) I always enjoy everything “at the time” and make the best of things.’

‘Volunteer with odd jobs at the village hall. Help set up functions at the village hall. Keep neighbour’s garden watered when away.’

‘Making friends with others. Easy to talk to. Help others with sewing etc.’

‘I enjoy my sessions at the day centre. I can play the keyboard to accompany the singing.’

‘I still play a role as a member of various committees and as a clergyman I still take services when the vicar is away. I suppose that the fact that I am still asked to return is a comment that I am in the early stages of Alzheimer’s.’

Respondents to the DFCSurvey

One example comes from a younger person with dementia, who felt it ‘sounds a bit funny, but I must say I’m having the time of my life’. This person described being involved in things he never thought he would have been and has made new friends since his diagnosis. His contributions include attending professional events to speak about his experiences with dementia. This motivational example truly demonstrates how with the right support, people with dementia can live full and active lives with genuine purpose and value.

The following case study is a powerful example of how an individual with dementia contributes to his community, building on his skills as a former headteacher. The case study is in his own words.

Case study

Hearing children read as a volunteer

Accepting the realisation that one’s career is about to come to a close because of the difficulties which having dementia can present provides one of those ‘cliff edge moments’ post diagnosis. In my case I was still actively head of a very large primary school, and the thought of a vacuum to replace my enjoyment and sense of purpose and engagement with children and staff was disturbing. Consequently three months after adjusting to the confirmed diagnosis and subsequent retirement I was fortunate to be able to begin weekly visits into a primary school close to where I live in order to listen to children read. I really enjoy the sense of helping and the friendly children and staff.

The staff know my diagnosis and always treat me respectfully. I like wearing a tie and presenting in a professional way. The children benefit from a friendly adult’s attention and interest and always respond positively, which is quite uplifting. I have taken some Alzheimer’s Society books for children into the school for the children and staff to read and comment upon which was also very positive in raising awareness and understanding.

One boy in the reading group recently commented that he’d seen me in a magazine article in his doctor’s waiting room. I wondered what he was going to say next. ‘Did you?’ I asked with interest and some surprise. ‘Yes’ he replied with a broad smile, ‘and I know your first name!’ The article was a very positive piece about not being defined by one’s dementia – clearly it worked with that young man!

People with dementia are individuals and it will not be of interest to everyone to participate more broadly in the community. This is an equally valid response which reinforces the importance of not making assumptions about what people with dementia want.

However, it is also critical that members of the community and people with dementia themselves acknowledge that people living with the condition can continue to make a positive contribution to their communities. The range of negative responses and sense of hopelessness in some of the answers to this question demonstrate a real need to empower people with dementia.

This empowerment can come about by engaging those living with the condition in the design of dementia-friendly communities. People with dementia must always be at the centre of the work on dementia-friendly communities. Specifically, time should be taken to find out what interests and motivations people have to ensure that their needs and aspirations are met.

4.2 Perceptions of people with dementia from the general public

There is significant goodwill in the community to help people with dementia live well. The YouGov poll of UK adults found that only 3% think that people with dementia don't have anything to offer their communities.

Respondents could give multiple responses to the question 'do you think that you have a role to play to support people with dementia in your local community?' It was found that:

- 40% of people think everyone has a role to play.
- 13% think it's their business because they have friends and/or family in their local community who have dementia and they support them.
- 11% answered that they have a role to play for an unspecified reason.
- Only 1% answered no because people with dementia cannot be part of the community and 6% said no for another reason.

There are also positive perceptions about the concept of dementia-friendly communities. The YouGov poll revealed that:

- 74% of UK adults think supporting people with dementia to be part of the community would help to reduce stigma.
- 47% of people think that dementia-friendly areas would be nicer places for everyone to live.
- 33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- Only 21% of people thought that supporting people with dementia would be good for the person with dementia, but wouldn't benefit anyone else.

It is significant that 74% of UK adults think that supporting people with dementia to be part of the community would help to reduce stigma. The creation of dementia-friendly communities may therefore have significant potential to allay some of the fears surrounding dementia. A recent poll suggests dementia is now one of the most feared conditions for either a loved one or the individual to develop (Populus, 2012).

People are also worried about the care they will receive as they age. The Low expectations report (Alzheimer's Society, 2013b) demonstrated that 70% of survey respondents said they would feel scared about moving into a care home in the future. A dementia-friendly community must be an enabling environment that supports individuals along the continuum of care requirements they will need. This means helping people live longer in their own homes while it is safe to do so and supporting the transition into care as required. There is a key role for commissioners, care providers and housing bodies to support people's capacity to live independently, transition to care and dispel the negative perceptions of care homes.

There is a fantastic opportunity to act on these findings. Across the UK, there are committed individuals who recognise they have a role to play in supporting people with dementia and the benefits for all that a dementia-friendly community can bring. Part of becoming a dementia-friendly community involves mobilising this support into action, with individuals, organisations and communities working in partnership with people with dementia.

There are pockets of good practice that demonstrate the ways in which organisations and communities are working together to help people live well with dementia, and these are discussed in the following sections. In these communities, action groups, alliances or networks of interested parties have tapped into the groundswell of local support to help people with dementia and their carers live life the way that they want to, and to engage in their communities as they see fit. With sustained national leadership teamed with localised calls for action, small steps can be taken immediately to empower more people with dementia to feel part of their community.

5 What does the evidence tell us about the barriers that people face and the support they need to live well in their area?

Summary

This section highlights that while people with dementia face barriers to engaging with their community, it is possible to put things in place that could make their day-to-day lives much better.

People face psychological and emotional barriers to being able to do more in their community, alongside physical issues. The most common barriers are:

- a lack of confidence (69%)
- being worried about becoming confused (68%)
- being worried about getting lost (60%)
- mobility and physical health issues (both 59%)
- not wanting to be a burden to others (44%)
- lack of transport (33%).

The YouGov poll found that UK adults think that the barriers that people with dementia face are due to issues such as stigma or lack of understanding about dementia from the general public (65%), a lack of formal and informal support from others to carry out the activities they want to (57%) and a lack of appropriate activities for people with dementia to do (53%).

To help support them, people with dementia would like:

- more care, support and services to do things in the community, including more opportunities to participate and help to attend activities through a befriender (35%)
- better or more transport (14%)
- improved health (10%) related to either their dementia or another condition
- information readily available to help people make decisions about their day-to-day lives and the activities they engage in.

Summary

Within a dementia-friendly community:

- People with dementia know that when they leave the house or meet with others, their condition will not be cause for embarrassment or discrimination.
- To overcome their lack of confidence, worry and concern, the stigma that people with dementia face needs to be challenged. Broad-reaching awareness-raising needs to happen across the community, from the shops along the high street to the community organisations and service providers. Particular attention needs to be paid to seldom heard communities.
- People with dementia can be confident that services such as transport will be consistent and reliable, as well as responsive and respectful to their needs. People with dementia have access to information in a range of formats that they can understand and respond to.

5.1 What are the barriers to people living well in the community?

The DFCsurvey asked respondents about the barriers that have stopped them doing some of the things that they used to. This was a fixed-answer question and respondents were asked to answer whether each barrier affected them.

The findings show that for many people with dementia, significant barriers are preventing greater community participation and involvement. In addition to problems with their physical health and environmental obstacles, people interviewed in this research also revealed psychological and emotional barriers to being able to do more in their community.

As Table 9 shows, people with dementia found the biggest barriers to doing the things that they used to do were:

- a lack of confidence (69%)
- being worried about becoming confused (68%)
- fear of getting lost (60%)
- mobility difficulties and physical health issues (both 59%)
- not wanting to be a burden to others (44%).

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Table 9: Barriers that people with dementia face

DFCSurvey: If you have stopped doing some of the things that you used to, can you tell us what have been the barriers to doing them? (Please answer each one)

	Yes (%)	No (%)	Don't know (%)
Physical health	59	37	4
Mobility difficulties	59	38	
Lack of transport	33	62	5
Lack of support from family or friends	18	77	5
Lack of support from services	24	64	12
Lack of confidence	69	25	
Worried about getting lost	60	34	6
Worried about becoming confused	68	26	6
Lack of opportunities	33	55	11
Don't want to be a burden	44	43	13
Fear of how people will react	28	57	14
Feel unwelcome	18	68	14
Nothing I enjoy available	18	62	21

Developing dementia can have a significant impact on self-confidence, with people often doubting whether they can continue the life they once had. Confidence is a complex concept. Most definitions can be summarised by thinking about a person's self-belief that they can achieve what they set out to, and also their trust and belief that things will turn out well (Centre for Confidence, 2013).

Many of the comments throughout this report indicate that most people with dementia have neither the belief that they can do more nor the optimism to hope that more is possible. Those interviewed and surveyed for this report described how fear, anxiety and worry now affect their ability to conduct day-to-day tasks and their willingness to try new activities.

'I can remember mother saying "it's a confidence thing... you lose your confidence as you get older" and I suspect that's a lot of it, you haven't got the confidence... to go and have a look or ask somebody.'

Respondent to the DFCSurvey

Among UK adults surveyed for the YouGov poll, 65% of people felt that stigma or lack of understanding about dementia from the general public was the biggest barrier preventing people with dementia being able to participate more fully in their local community.

It is important to note the way that stigma affects many aspects relating to dementia and acts as a barrier to people's community involvement. Stigma stops people from talking about their concerns at an early stage and prevents people from obtaining a timely diagnosis. Misinformation and lack of awareness among health professionals does little to assist this situation. One of the interviewees started experiencing the symptoms of dementia when he was 59 and spent years trying to identify what was happening to him. When his family suggested it may be dementia, they were told 'Don't be stupid, younger people don't get dementia'.

This stigma also creates an environment that restricts the involvement of people with dementia. It affects people's confidence to go out in public as they fear public reactions or doubt their ability to get help if they need it. Evidence from the interviews with people with dementia and their carers highlights the daily barriers that people experience due to stigma or lack of community understanding.

'We used public transport and it was difficult when he started to sit on the floor of the bus – people just didn't understand and a lot of people didn't like this. Also when he got lost at the airport the people in authority believed him and ignored me – in the early stages he was very convincing.'

'He says that he is getting old and doesn't remember things – we never use the word "dementia" (his brother had dementia and died in a care home). I will tell people he has memory loss if they need to know.'

People with dementia and their carers from seldom heard groups

36 What does the evidence tell us about the barriers that people face and the support they need to live well in their area?

Part of building understanding of dementia among the general public involves ensuring that they appreciate the impact that dementia has on the individual and the role that they personally can play in encouraging and supporting people to be more active in their local area.

Case study

N is from Northern Ireland. He has Alzheimer's disease and lives at home with his wife who works full time.

N used to attend a day centre but stopped enjoying it when they tried to get him to participate in activities that he couldn't do. N does go to a friendship group and finds it good to have some structure and routine as it can be very lonely spending all day in the house. N depends on his wife and will not travel by public transport.

He finds frustration a big problem and has experienced low moods and suicidal thoughts. The frustration can stem from family members thinking they know the right way of dealing with the dementia but in fact they can quite often make him feel worse. N explained that people have a habit of being patronising which makes you feel inferior or like a child. N thinks that talking about dementia is important and people need be trained in how to treat people with dementia with respect.

'Before the dementia, I used to be an entity in lots of areas; people looked up to, and came to me for help. And all of a sudden I have lost all of that control. People can be patronising but we should be treated as individuals not like an idiot.'

Alongside stigma, respondents to the YouGov poll believed that other barriers to people with dementia participating in the community included a lack of formal and informal support from others to carry out the activities they want to (57%), followed by a lack of appropriate activities for people with dementia to do (53%).

In addition, 33% of people with dementia from the DFCsurvey felt that a lack of transport was a barrier and 43% of respondents from YouGov identified that public transport not being suited to people with dementia was stopping people from participating more fully in their local community. Problems relating to transport and being able to attend activities were consistently raised by DFCsurvey respondents.

5.1.1 The experience of people from seldom heard groups

Alzheimer's Society was particularly interested in exploring the barriers that people face when they belong to different communities, often underrepresented in the broader literature and research. Some issues were more pronounced such as stigma and transport issues:

'Access is a problem in a rural area, there just isn't the transport to get to things.'

'Getting out and about is difficult, we rely on support from carers/family as we struggle by ourselves and public transport is difficult sometimes.'

People with dementia and their carers from seldom heard groups

Interviews conducted highlighted the importance of community connection and companionship. One carer described how her mother really enjoyed joining her whenever she went out. Having experienced a significant exclusion from her local South Asian community, the carer commented on how her mother seemed to miss female company in particular, as all of her mother's female friends had stopped visiting.

Another highlighted the value of continuing connection to community:

'In the early stages it would have helped to have company for him, he enjoyed his own community and hearing people from his home country talking.'

People with dementia and their carers from seldom heard groups

Research into the barriers to social participation for all people from seldom heard communities shows that many face additional pressures or difficulties. People from black, Asian and minority ethnic groups, for instance, may face problems around both accessing health services and engaging in activities, especially where people feel that practitioners do not have cultural competence, hold particular stereotypes, or make assumptions about the care that people want (Moriarty et al, 2011; All-Party Parliamentary Group, 2013).

38 What does the evidence tell us about the barriers that people face and the support they need to live well in their area?

There may also be different power relations and concepts of belonging within families or religious expectations that affect on people's ability to access appropriate care (Rauf, 2011). This can mean that people with dementia from seldom heard groups, for example gay, lesbian, bisexual and transgender groups, people with learning disabilities, ethnic minorities or younger people with dementia will come up against additional barriers.

It is important to support particular communities through tailored and appropriate information that recognises cultural and linguistic differences. More focus needs to be placed on establishing the impact that dementia has in seldom heard communities and opportunities for better service provision.

5.2 What support do people with dementia require to do the things that they would like to do in their local area?

The DFCsurvey explored what people with dementia felt would support them to do what they would like in their local area. This was an open-ended question and many respondents identified more than one type of support. The answers to this question have been grouped to provide a statistical breakdown. Table 10 shows these results.

Table 10: Support needed in local areas

DFCsurvey: What might help you to do the things that you would like to do in your local area?	
Support identified	(%)
Transport:	14
ability to drive again	1
better bus service	2
other mention of transport	11
Better health:	10
lessen symptoms of dementia	1
better physical health	2
other health mention	7
More care/support:	35
befriender or additional care	6
more organised activities	14
other mention of care/support	15
Financial assistance	5

DFCsurvey: What might help you to do the things that you would like to do in your local area? (Continued)

Support identified	(%)
Not applicable:	34
N/A as can't do anything	1
N/A as I am able to do what I want to	9
'None', 'nothing' 'nil'	23
Don't know	11

The top priority for 35% of respondents involved having more care, support and services to do things in the community. Within the category of care and support, people described wanting more opportunities to participate and help to attend activities. Many comments sought the help of a befriender to assist with travelling or building confidence to do more activities. Some identified that a befriender could remind them of when things are on or help them with the motivation to participate more.

In addition:

- Better or more transport also featured strongly. 14% of people with dementia made a reference to transport including being able to drive again and the use of buses.
- 10% of people also made a reference to their health, relating either to their dementia or other conditions that affect them.
- Many highlight the lack of information available to them to make decisions about their day-to-day lives and the activities they engage in.
- 11% of people with dementia answered 'don't know' to what support might help them do more things in their local area.

40 What does the evidence tell us about the barriers that people face and the support they need to live well in their area?

Responses included:

‘Transport for short rides and a cup of coffee.’

‘To know what is available and people to link up who can take me if my family can’t.’

‘If services were a lot more accessible to all no matter what their disability or need.’

‘Very limited activities in my area. Once a month I visit a memory cafe.’

‘I think more information. I have a wonderful family but there are many who are alone. The GPs in my experience offer little or no support.’

‘I need someone to suggest and organise and motivate, also transport outside my area is difficult.’

‘I am not well enough to do any of the things I used to enjoy doing.’

‘Don’t know what’s in my area through lack of confidence.’

Respondents to the DFCSurvey

People with dementia need more support to maintain involvement in their communities. This support must be accessible, appropriate and tailored to the individual. A priority must be placed upon ensuring that people with the condition are engaged to identify what form of support is most needed in their local area and empowered to believe that they can continue to play a role in their community.

6 Solutions and examples

This section explores in detail key solutions and guidance for communities working to become dementia friendly. It pulls together the findings from the report, further external evidence and examples of projects that are already making a difference for people with dementia. This information is collated to shape a definition of a dementia-friendly community. Ten essential areas are identified for communities to focus on as they set out to become dementia friendly.

This section does not include proposals for the infrastructure that should support a dementia-friendly community, such as establishing a local Dementia Action Alliance or similar network. Communities should sign up to the recognition process for dementia-friendly communities to ensure that they are working towards the necessary structure, core values and criteria. In addition, communities will need an understanding of the evidence in this report.

Definition: A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

To achieve this, there are 10 key areas that dementia-friendly communities should be working towards:

1 Involvement of people with dementia

Shape communities around the needs and aspirations of people living with dementia alongside the views of their carers. Each community will have its own diverse populations and focus must include understanding demographic variation, the needs of people with dementia from seldom heard communities, and the impact of the geography, eg rural versus urban locations.

2 Challenge stigma and build understanding

Work to break down the stigma of dementia, including in seldom heard communities, and increase awareness and understanding of dementia.

3 Accessible community activities

Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.

4 Acknowledge potential

Ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities. Build on the goodwill in the general public to make communities dementia friendly.

5 Ensure an early diagnosis

Ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.

6 Practical support to enable engagement in community life

Deliver a befriending service that includes practical support to ensure people with dementia can engage in community life as well as offering emotional support.

7 Community-based solutions

Support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive, high-quality care homes. Community-based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.

8 Consistent and reliable travel options

Ensure that people with dementia can be confident that transport will be consistent, reliable and responsive and respectful to their needs.

9 Easy-to-navigate environments

Ensure that the physical environment is accessible and easy to navigate for people with dementia.

10 Respectful and responsive businesses and services

Promote awareness of dementia in all shops, businesses and services so all staff demonstrate understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business.

This section now looks at these key areas in more detail, highlighting what should be done and providing examples of where it is happening.

6.1 Awareness and public understanding

Public awareness and a better understanding of dementia are needed to break down the stigma that people living with the condition face. Nearly two thirds of UK adults surveyed in the YouGov poll agree that stigma is a barrier to people with dementia being active in their community and only 21% think that the public's understanding of dementia is fairly good or very good. There is therefore a widespread recognition of the need for greater awareness and understanding.

Misinformation about dementia, particularly in some cultural communities, was also identified as an issue, and many people in the general public fear the condition. A key element of a dementia-friendly community is ensuring that people with dementia no longer feel ashamed or embarrassed by their condition. Increasing community understanding is paramount to breaking down the stigma of dementia and improving diagnosis rates.

‘Lots more information for people. More awareness about dementia so people understand. More information for people to reduce stigma but this is better than it used to be.’

‘Education and awareness of dementia especially to the regular person in the community. Talking about dementia is important.’

‘Talking about dementia and training (including for churches and education in schools).’

People with dementia and their carers from seldom heard groups

For people with dementia to feel confident, all members of the community including friends, neighbours, the public, shops and businesses must have an understanding and appreciation of the condition. There are many inspirational projects taking place to improve public awareness of dementia. As explored in the case studies below, many projects will have positive outcomes for more than just people with dementia. For instance, projects focused on intergenerational learning are also attributed with countering ageism in society and specific projects with cultural communities may help in building social cohesion (World Health Organization, 2007).

Education campaigns need to be tailored to specific audiences, presented in a range of formats that are appropriate and easy to access – eg acknowledging where English is a second language.

Where is this working?

Dementia Friends

Alzheimer's Society is running a national initiative to create a network of one million Dementia Friends across England by 2015. Parallel programmes are being also developed in Wales and Northern Ireland.

Funded by government, volunteer Dementia Friends Champions are being trained to lead education sessions on dementia. Across the country, the people that attend these 45-minute sessions become a Dementia Friend and learn valuable insights into the condition and how to be more responsive to the needs of people living with dementia in their community.

Dementia Friends can make a real impact in organisations and businesses in the community. Recent Dementia Friends information sessions have ranged from coffee mornings in workplaces to sessions with family and friends on a camping holiday, and even an impromptu one at Glastonbury Festival. In secondary schools 600 pupils have been involved and there are 750 new Dementia Friends at Lloyds Banking Group.

Other examples include the Courtyard Hereford Centre for Arts where all front-of-house staff now are now becoming Dementia Friends. It is anticipated that this simple training session will help drive better service and enable more people with dementia to visit the centre. For more information or to sign up to become a Dementia Friends Champion go to dementiafriends.org.uk

Intergenerational schools – creating a 'dementia-friendly generation'

Twenty schools have formed a 'pioneer group' to develop dementia awareness sessions for children and young people across England. Schools are leading the way with their own local approaches and have run varied activities to aid learning about dementia, including dementia awareness lessons, choir visits to dementia care homes, debates and art, drama and music projects.

Some of the most powerful experiences have happened when students engage with people with dementia in their community and gain real insight into not only dementia but also wider issues such as learning about compassion, understanding of older people, and illness. For example, young people from schools in Kent have interviewed local people with dementia and then created life history story books based on their experiences. A highly successful event was then held, where local schools came together and included a presentation of the books to those that had been interviewed.

Connecting Communities

Connecting Communities is an Alzheimer's Society project that will see volunteers from black, Asian and minority ethnic communities designing and delivering awareness-raising activities that are culturally appropriate for their communities. Across eight London boroughs, Alzheimer's Society aims to:

- raise awareness of dementia among diverse communities across different generations
- highlight the importance of seeking an early diagnosis and explain locally how to do this
- build a local volunteer base that is reflective of the demographics of the area.

Project findings will inform a black, Asian and minority ethnic commissioning toolkit for local authorities and volunteering best practice for the UK and London.

6.2 Appropriate care and support

Over half (59%) of people with dementia responding to the DFCsurvey identified that their physical health had stopped them doing the things that they used to do. People with dementia are the main users of health and care services and are more likely than others to experience physical comorbidities that dramatically affect quality of life.

Being a dementia-friendly community does not replace the need for more effective spending and better quality health and social care. It does, however, recognise that integrated care for a person with dementia is holistic and must tap into expertise across health and social care in partnership with the community, voluntary sector and housing associations.

While there is an opportunity for dementia-friendly communities to alleviate some of the pressure points on the system and shift funding towards preventative services, funding for health and social care remains in crisis. A key factor for supporting a dementia-friendly community is ensuring that there is a fully funded health and social care system that delivers integrated and person-centred care for people with dementia and their carers. Within this, support for carers must also be recognised as a key priority.

6.2.1 The cost case for appropriate care and support in the community

An analysis of the costs associated with the individual dementia care pathway forms part of the economic case for dementia-friendly communities and the importance of getting integration of the health and social care system right.

A dementia-friendly community should be a place where people with dementia are given assistance at home earlier, reducing the risk of comorbidities or falls, fractures or urinary tract infection, and helping reduce stress and fatigue in their carers. More community-based solutions should mean that the person with dementia requires fewer admissions to hospitals and remains in their own home for longer.

When taking into account the possible substitution effects, that is exchanging community care for inappropriate residential and hospital care, dementia-friendly communities have the potential to generate savings. Even when the full cost of home help, respite care, therapies and medication in the community are included, the cost of residential and acute care exceeds the cost of community care.

Living in the community with dementia (excluding the initial memory services assessment) is estimated to cost £24,128 each year. This includes the cost of an integrated health and social care package, together with respite, therapies and medication. A year in residential care costs an average of £35,424. For each person who is able to live at home there is a saving of £11,296 per year or £941 per month. Extending this out, if just 5% of admissions were to be delayed for one year as a result of dementia-friendly communities, there would be a net saving of £55 million per annum.

To start realising these costs, it is essential that people with dementia are provided with an early diagnosis to ensure that they receive timely support and that long-term planning decisions are made by the person with dementia while they have capacity. Yet, less than half of people living with dementia in the UK have a diagnosis and there is unacceptable variation across nations (Alzheimer's Society, 2013a). Information following a diagnosis is vital. The dementia guide published by Alzheimer's Society brings together resources to help people to understand their diagnosis, to live well with dementia, to access available treatments, services and support, and to plan for the future.

Dementia-friendly communities must be environments where an early diagnosis and effective post-diagnostic support are the norm. In particular, integrated and personalised care is essential for people to live well with dementia. People with dementia currently have to juggle between complex healthcare arrangements provided by multiple providers. A recent survey confirms that the coordination of care is not meeting people's needs. Less than half of the respondents answered that community services worked well together and only two thirds thought that hospitals work well with GPs and others (Department of Health, 2012).

More effective care pathways, reducing the unnecessary and extended stays in hospital by people with dementia and focusing attention instead on reablement and capacity in the community care sector, could generate substantial savings across the entire health system (Alzheimer's Society, 2009). Better care planning has the potential to improve patient experience and care outcomes. Following an integrated care pilot in north-west London, the evaluation demonstrated a marked increase in diagnoses of dementia and increased provision of care plans for people with dementia (Nuffield Trust, 2013). These are crucial elements in delivering better care for people with dementia.

Where is this working?

Early diagnosis pilot projects

Alzheimer's Society ran two early diagnosis pilot projects to increase diagnosis rates in Dorset and Warwickshire. Activity included:

- targeting media outlets to highlight the issue of under-diagnosis
- engagement with local stakeholders
- dementia awareness events throughout the community
- distribution of Worried about your memory? materials
- engagement with local GPs and health providers.

Impressively, both areas saw dramatic improvements in the uptake of information on early diagnosis and the number of people acting on concerns about dementia. There has been an increase in memory clinic referrals and 60% of GP practices in the communities reported an increase in the size of their dementia registers over the period of the pilot project.

This demonstrates that a combined approach, incorporating public awareness raising, media activity, health professional engagement and stakeholder engagement, can improve awareness of dementia.

Think Again programme

The Think Again programme, by Avon and Wiltshire Mental Health Partnership NHS Trust, demonstrates effective post-diagnostic support that goes beyond the simple provision of information. Over eight weeks, therapeutic group sessions are provided to people with dementia and their carers. Two staff remain constant for the entire course and each session focuses on a particular aspect with part of each session split into two groups: people with dementia and carers.

Participants explore strategies to cope with communication difficulties, relationship changes and memory. They also look at goal-setting to reignite motivation and consider ways to continue to do things they have always done where possible or in a different way. The knowledge, the small lifestyle changes and the coping strategies that are shared in the group can dramatically improve participants' wellbeing.

This comment from a participant illustrates the powerful impact of the programme:

'This group was absolutely fantastic. I was reluctant to go at first because I wasn't sure that anyone else would understand what I was going through. The team were very understanding and I learnt so much about my condition that I now feel more confident. My daughter attended with me as I'm widowed and she has said how useful it has been to learn more about the condition and this has now enabled us to discuss the condition with more ease.'

Hampshire Dementia Adviser Service

Recognising that people with dementia want choice and control over how they live their lives, Hampshire County Council has been instrumental in driving local improvements for people living with the condition. In Hampshire alone, there are 18,500 people with dementia and by 2030 the number of people living with the condition will be approaching 35,000.

The new Hampshire Dementia Adviser Service is available to anyone with a diagnosis or suspected of having dementia. Provided by Alzheimer's Society and Andover Mind, the service focuses on wellbeing rather than illness and supports people to think about how they can come to terms with and live well with dementia.

Gnosall Medical Practice

Gnosall in the West Midlands is working to improve dementia diagnosis rates, as part of a wider project on dementia. In this project, a model in which services have been integrated into a single organisational entity has been developed, led by GPs who hire specialists directly.

As part of this model practice staff, known as Elderly Care Facilitators, are integral to improving the diagnosis experience. Gnosall Medical Practice provides a Memory Clinic and related services in-house. The arrangements bring the specialist expertise of psychiatry into the practice, and the practice retains clinical responsibility for patients.

Elderly Care Facilitators identify those who may need the service and then become champions for such patients. The facilitators are recruited from those with an existing enthusiasm and wealth of experience in health and social care but are local, knowledgeable and enthusiastic about caring for those with dementia.

They visit people suspected to have memory problems and do a structured assessment under the supervision of the consultants. They befriend and act as an intelligent companion and advocate for the patient and family. They also liaise with other practice staff, specialists and other agencies.

6.3 Care, support and networks

People with dementia and their carers surveyed for this report identified that to regain their confidence to go out in the community there is the need for more or better care and support. Broadly, this relates to the following key areas:

- People with dementia would like someone to support them to get out and about, for example to travel with them and even suggest activities to be involved in.
- People also asked that there be more appropriate activities for them to go to or for activities to be more frequent.

Ways of achieving this desired access to activities and improved support to travel are explored in the following sections.

6.3.1 Extended befriending and one-to-one support

Befriending and one-to-one support were frequently mentioned by DFCsurvey respondents. Befriending is typically characterised as offering companionship and emotional support to people in need. However, in addition to wanting more social contact, people with dementia identified a need for more help to travel to activities, or be motivated and reminded of activities that are available. This support is also mentioned across other research (Tower Hamlets Friends and Neighbours, 2012; Innovations in Dementia, 2011).

‘A support worker just to be with me and perhaps accompany me on walks or for a drink in the pub as I used to be a barmaid and this is a comfortable environment for me.’

‘I can do things “when I don’t forget”. Need people to help organise.’

‘Help with taxi fares, have someone to go shopping with.’

‘I would like a befriender to support me to go to needlework class.’

‘Somewhere to go, meet people, be able to go out in the community. Someone to call in to say hello. Information about things that are going on locally so that I could get involved and not feel so lonely.’

Respondents to the DFCsurvey

It is vital that this type of support is available in any dementia-friendly community. It could take the form of ensuring that every area has a befriending service that includes practical support with engaging activities as well as emotional support. Some successful models explored in the case studies involve a pool of trained volunteer befrienders who are able to offer this support to people with dementia. Other schemes such as time banking might be valuable in rebuilding confidence and community involvement for people with dementia. These schemes, where every hour spent volunteering earns a ‘credit’ of somebody else’s time, foster greater community involvement and remind people of the skills they have or are capable of developing (Cahn in Edinburgh timebanknetwork, 2012).

Where is this working?

Active Life for Frail Isolated Elders (ALFIE), Tower Hamlets

The ALFIE project, run by Tower Hamlets Friends and Neighbours, recognised that people need to be engaged in activities inside and outside of the home. One-to-one accompanied trips to local parks, shops, museums and cafes are conducted in addition to home-based activities such as reflexology, crafts or seated exercise. For people with dementia, reminiscence activities have been implemented, with people strongly valuing being able to share their life stories.

A related project called the ALFIE club is being run in partnership with a range of other organisations including sheltered housing schemes, centres, and other voluntary organisations. Events, such as school choirs, singers, pampering sessions, a visit by a city farm with animals, a reminiscence session by a Bengali storyteller, tea parties and group seated exercise activities have been held throughout the borough. Activities are chosen by each client according to their needs and wishes, and as a result participants describe feeling more connected and engaged with the community.

Happy, Safe, Out and About (buddy scheme)

Crawley Dementia Action Alliance is setting up a volunteer buddy scheme where the needs and wishes of people with dementia are matched with the skills and interests of volunteers. Across the local community and all adult age groups, volunteer buddies will be sought out to help in the home, in group environments and going out and about.

6.3.2 More organised activities that are appropriate to needs

People with dementia have asked for more organised activities that are specific and appropriate to their needs. People wish to be involved in a range of activities spanning from music events to faith-based activities. Across all research there is recognition of the need for more tailored services that reach out to all groups, across different ages, stages of dementia and linguistic or cultural backgrounds.

Where people stop attending services or groups, attention should be paid to uncover the reasons for this and whether more support could help people to stay engaged. Participation in faith-based groups also featured throughout the interviews, and there is a role for places of worship to work with local areas to ensure that people can continue to practice their religion.

Adaptations to the way that staff provide information or alterations to the physical environment, such as clear signage, can open up opportunities for people with dementia to participate. At the heart of this, people with dementia need to be engaged and consulted on how to make services more accessible to their needs. Walking in the shoes of a person with dementia, by accompanying them to activities, is a powerful way to gain a first-hand insight into the obstacles that people with dementia face.

One way to develop more services and activities for people with dementia involves making the mainstream work for more people. For instance, 15 local Age UK services across England are working to make the generic services they offer more inclusive of people living with dementia. Across the country, as the case studies below show, there are ways of adapting existing leisure, entertainment and support activities to make them more accessible to people with dementia. One of the first steps involved in doing this for a dementia-friendly community involves assessing what services are available locally and what people with dementia use and would like to use. From this baseline, specific services can be prioritised and tailored to be more inclusive for all people, not only those with dementia.

An important aspect of creating a dementia-friendly community is ensuring that people with dementia maintain and develop new relationships and social networks. As people with dementia are at a higher risk of social isolation, services and organisations need to take a personalised outreach approach that encourages participation.

Where is this working?

Age UK

Age UK Lancashire linked up with the Dukes Theatre to develop events that, while accessible to all, would be adapted to be as welcoming as possible to people with dementia. Staff attended training and a checklist was prepared to work through easy changes to the environment and set-up to help people with dementia. Having now hosted a few films with a 'Journey Café' offering refreshments and Dementia Advisers available on site, feedback from attendees has been really positive:

'Lovely meeting people who are not afraid to talk to us! Stops us being isolated at home.' (Feedback from attendees gathered by Age UK Lancashire.)

Worcestershire County Council Museum Services

Seeing that people using their local Dementia Café needed a boost in confidence to get back out in their communities, Alzheimer's Society in Worcestershire teamed up with Worcestershire County Council Museum Services to see what their local museums might be able to offer.

Support Services Manager, Gillian Read, found that people with dementia in their community:

'Do not feel confident to go out in the same way that they used to. They may be scared of not knowing where the toilets are, how accessible the place is, or whether they can they cope if something happens.'

As a way to rebuild some of that confidence and enhance opportunities for peer support, in December 2012 Hartlebury Museum hosted Dementia Café and Singing for the Brain® participants for a day in the museum. Using a pictorial feedback form with sticky notes for extra comments, attendees were also asked how dementia friendly the museum currently is. Feedback ranged from improving signage and lighting to relocating the outside toilets inside for better accessibility.

Following the event, 20 museum staff underwent dementia-awareness training and over the next 12 months, a planning committee will be looking at more ways that it can support people with dementia.

A range of new events and partnerships are also being taken forward across the county council, including more dementia training and a summer garden party with entertainment from the English String Orchestra.

Circles of Support for People with Dementia, South of England

Circles of Support for People with Dementia is an approach that aims to reduce the need for paid support and promote people's connections within communities.

Drawing together friends, family, neighbours, volunteers as well as paid staff, the Circle works with the person with dementia to think about what they would like to do in their life, and then supports them to make these things happen.

Everything developed in the project is highly personalised and suited to the individual. For example, individuals may be supported to take part in a local gardening group instead of attending a day centre, they can be introduced to new networks to create friendships or supported to progress interests such as computer skills.

People with dementia involved in the project are making and re-establishing connections more widely within their communities. For instance, one woman was unable to go to her much-loved singing group, following a move to a care home. Knowing that she was a regular churchgoer, one member of the Circle contacted the vicar who then made enquiries among members of the congregation who knew this woman well. A volunteer was found who was happy to accompany her to the singing group and she was able to join in regularly – meeting up with all her friends there again.

Early evaluations have found a critical need for flexibility. For some this has meant creating very informal Circles, being personal not prescriptive in their meetings, and tailoring communication to each participant in the Circle. With the project drawing to a close in March 2014, work is taking place to help dementia support workers, advisers and others who have been involved shape their practice in the future.

The National Development Team for Inclusion and Innovations in Dementia have been running pilots at four sites across the South of England:

- Mid-Devon, in partnership with Upstream
- Dorset, in partnership with Alzheimer's Society Dorset
- Hampshire, in partnership with a range of voluntary and other organisations
- West London, in partnership with a range of voluntary and other organisations.

Dementia-friendly churches, North West Midlands

Challenged by a District Council CEO to respond to the changing demographics in their area, the Anglican Diocese of Lichfield is driving forward an agenda to offer care, support and activities for people with dementia. With almost 600 churches across the West Midlands, the Diocese serves a population of nearly 2 million. The diocese is now part of a Dementia Action Alliance and church members are signing up to become Dementia Friends.

As part of an Age on Agenda symposium, a multidisciplinary workshop on dementia was held. In the action plan that followed, collaborative ventures with partners from both the voluntary and the statutory sectors, as well as bespoke training for local parish churches, were agreed on. Over 20 churches have expressed an interest in being part of a pilot project on becoming dementia friendly and further planning is underway with local charities and community organisations. Churches will look at ways to improve their environment, raise awareness, tailor church services, offer pastoral care and become person-centred.

Cuimhne: Irish Memory Loss Alliance

The Cuimhne initiative aims to make the Irish community 'the first ethnic minority community to be memory-loss friendly in Britain'. A call to action has gone out to the Irish community in Britain, funding bodies, businesses, statutory services and the media to address the isolation and exclusion of people experiencing memory loss. Connections are being fostered with business and construction networks, county associations and councillors.

The emphasis throughout their projects is on personhood, recognising individual life history, cultural, social, emotional and spiritual needs for both a person with memory loss and their family carers. The initiative will look to build community alliances, improve awareness and understanding, develop and strengthen networks, lobby for political action and deliver memory loss training.

6.4 Transport

Ensuring that a community has accessible, safe and reliable forms of transport is critical to building community participation. For people with dementia, the impact of issues relating to transport is far-reaching and has a serious effect on overall confidence, sense of independence and ability to make decisions. The issues people face are diverse. For instance, people living in rural areas describe a lack of transport as an issue, while those living in urban areas feel worried about getting lost or confused on complex and busy transport options (Alzheimer's Society, 2013c).

Although there is a legal duty to ensure that a person can access transport services, which may range from providing wheelchair ramps, to helping someone get off the train safely, many people with dementia are not aware of these rights or do not feel they can rely on the transport providers to provide a consistent level of service. At a national level, improving transport should also include consideration of the blue badge scheme and how it can work for people with dementia.

Information about public transport often proves to be a barrier to people feeling confident and equipped to travel. People with dementia report difficulties when there are sudden changes to a journey (for example delays or cancellations), changes to signage or physical landmarks, issues with technology or feeling overwhelmed in crowded places. Increasing reliance on online and mobile technology for service updates is a barrier for people with dementia, who may not always use these forms of technology.

Clear communication and signage in a variety of formats, well-trained staff that have a visible presence on platforms or service points and providing a reliable and consistent level of service would remove some of the fears that people with dementia have about using public transport.

'Travel training', where a member of staff or the community assists a person with dementia to use new forms of transport early on following their diagnosis, can help. A 'travel buddy', where another passenger gets on at the same stop as the individual and offers a reminder when it is time to get off, is another example of practical assistance.

Community-based transport can assist people with dementia to maintain their involvement in the community. While services vary across local areas, community transport is usually pre-booked and often subsidised when certain criteria are met (eg age or disability). There is significant potential to coordinate services between local authorities, voluntary organisations and community organisations, and to utilise extra help from befrienders and volunteers in a dementia-friendly community.

Many people with dementia also indicate that they walk regularly. Local authorities and councils have a role to play in ensuring that public spaces are accessible and easy for people with dementia to navigate.

Where is this working?

Drivers for Change: dementia-friendly bus transport in Northumberland

Northumberland is developing a dementia awareness training package for local bus drivers for inclusion in the Certificate of Professional Competency. The large geographic area, diverse nature of communities within the different localities, higher older population, and range of bus operators, have made this a challenging but key part of the Ageing Well programme to help ensure people with dementia can continue to be active and engaged in their community.

The county has established the Northumberland Dementia Forums which draw together people with dementia, their carers and voluntary organisations. These groups raised difficulties about using local buses, especially for people in rural areas once the individual or their carer had to give up driving. Family concerns about the safety of and support available to their loved ones when out in the community were among the wider issues also identified. Some of the raised concerns were around bus staff responding to people with dementia and recognising mobility or sensory issues such as hearing loss.

The training development stage identified that a more sustainable and effective process is to work in partnership with the existing providers of driver training to develop an enhanced package that focuses on awareness and practical measures to support passengers. This is informed by people with different needs and stages of dementia and their families across the county through the forums.

6.5 Housing

Good housing and support enhance quality of life for people living with dementia. Community-based solutions to housing can prevent people from unnecessarily accessing healthcare, and support people to live longer in their own homes.

Increasingly across the sector, national housing bodies and local authorities recognise their role in improving quality of life for older people and those with dementia. The National Housing Federation (2013) has undertaken important research into how good housing can affect people with dementia. It recommends that commissioners work with their local partners to design home-based solutions to care and maximise opportunities for diagnosis and early intervention. New findings by the Housing Learning and Improvement Network (2013) also highlight the potential for extra care housing to reduce social isolation and loneliness in older people, and there are calls for greater involvement of local authorities in supporting better end-of-life care (Local Government Information Unit, 2012).

Where housing staff are appropriately trained in dementia, they have the ability to support people with a range of housing choices that can contribute to a better quality of life (Housing Learning and Improvement Network, 2013). When the transition from mainstream to specialist housing is required, it is important that people with dementia maintain their links to their community and can participate in new friendships and activities.

Extra care housing has the capacity to support a good quality of life for people with dementia (Housing and Learning Improvement Network, 2012). However, some people currently describe feeling isolated or a lack of acceptance from other residents. Positioning housing with care within the community offers both financial and social advantages for its residents and providers (Croucher and Bevan, 2012). A dementia-friendly community must be inclusive of people with dementia and their carers, no matter what care setting they live in. Therefore, an important aspect is ensuring that housing schemes are also integrated with health and social care services and involved in the local community.

All of these aspects have significant potential for improving quality-of-life outcomes for people with dementia and need to be considered as part of a dementia-friendly community. Local authorities need adequate financial resourcing to ensure that they can commission and offer a range of appropriate services to people with dementia. Focusing on preventative and early adjustments, in partnership with health and social care colleagues, could maximise the potential for savings and enhanced wellbeing.

Where is this working?

Your Community Matters, Merseyside

The Life Story Network, working with residential, home care and housing sectors, is delivering the Your Community Matters project. This project recognises that housing associations work at the front line of communities, often providing services that support their residents in the most challenging circumstances. Many, however, have come late to realise that dementia affects not only residents of specialist extra care housing schemes but also tenants in general and mainstream sheltered housing.

Life Story Network has provided dementia training to housing associations in Merseyside, including an introduction to understanding why documenting an individual's life story, be that through book, music or multimedia formats, can help people with dementia. Training has also extended to tenants who want to know more about dementia and how to respond in more positive ways.

Moving to the next stage of the project, there is commitment to map out what is needed to deliver a dementia-friendly community. Supported by key national housing organisations, the objective is to develop a collaborative dementia strategy and action plan for housing associations at the local level. Importantly, this will ensure better integration with NHS and social care strategies.

For example, as a sheltered housing provider, the Liverpool Housing Trust is facing increasingly complex needs in its applicants and tenants. Often scheme managers are the first to identify when someone is ill or not managing in the home. Some of these individuals have been diagnosed or have suspected dementia and part of the Trust's job is to ensure that these individuals receive the right type of support to get a diagnosis and maintain their own independence and continue to be supported at home.

Life Story Network has helped raise awareness among staff and tenants, including some focused training for tenants who then go out and spread awareness among their neighbours. Other training has involved working with family carers.

6.5.1 Care homes

Care homes also need to ensure that residents with dementia can maintain relationships and interests within the immediate environment and the broader community. Yet people with dementia in care homes describe mixed experiences in terms of their ability to participate in activities and engagement with the community (Alzheimer's Society, 2013b). An important shift is needed to move away from the perception of care homes as a 'last resort' and to build positive and active profiles in the community (Alzheimer's Society, 2013b; Mason, 2012).

As people with dementia are core users of care homes there is much that can be done by way of creating dementia-friendly communities. Better information is needed for those working across the sector in terms of training and information for the public and those looking to enter a care home. There is also significant potential for care homes to centre as 'community hubs' that integrate with neighbourhoods (Mason, 2012). This could include providing health and advisory services, sharing facilities for day services or opening up spaces to public use, such as meeting rooms or gardens.

Where is this working?

Dementia Pledge

Signing up to the Dementia Pledge demonstrates a care service's commitment to better dementia care. The Pledge has three aims:

- To ensure that people who deliver adult social care services fully understand and meet the needs of the person with dementia and their families.
- To ensure commissioners are committed to commissioning for quality, and only commission services from providers who demonstrate that their workforce understand the needs of people with dementia and are committed to providing excellent dementia care.
- To increase public awareness of excellent dementia care and make people intolerant of anything less.

Once signed up, care providers receive a copy of the Dementia Pledge logo to display. This means that these providers are working towards four key principles:

- 1 know the person who is living with dementia
- 2 quality care, quality life
- 3 everybody has a leadership role
- 4 value-focused care.

Services are encouraged to publish a record of their improvement and have access to a range of tools for improvement through Care Fit for VIPS.

Your handy guide to selecting a care home

Alzheimer's Society has produced a handy guide on selecting a care home. This document takes people through a range of essential criteria when choosing a suitable care home, from first impressions through to observing visitors, activities and cultural differences. The guide is designed to be taken into care homes by people with dementia and their families and provides an independent and objective guide to what makes high-quality care. This guide is available online only, and can be downloaded at alzheimers.org.uk/guidetoselectingcarehome

Plymouth Arts and Heritage service

Plymouth Arts and Heritage service is contributing to the dementia-friendly movement through its longstanding 'reminiscence service'. Staff from the service visit care and residential homes as well as the local hospital with a variety of the museum's handling objects which are used to rekindle memories in a fun and creative way.

6.6 Businesses and services

From the high street to the local corner store, there is a case for businesses to support people with dementia to use their services and facilities. Becoming dementia friendly may maintain regular customers but could also be a means of attracting new business and building positive reputational branding. For this section of the report, 'businesses and services' refers broadly to the activities that people with dementia described accessing or coming into contact with, such as retail shops and banks through to policing and fire services.

Local authorities have a leadership role to play in ensuring that business and services become dementia friendly. Promoting the dementia-friendly agenda in community forums, such as business councils or chamber of commerce meetings, can help to raise the profile of dementia. Businesses and services also have a central role to play in the work of their local Dementia Action Alliances or similar networks.

Ensuring that businesses and customer-facing staff have an understanding of dementia will help enhance the confidence of people with dementia. Further to this, it is crucial that all shopping methods as well as service provision – be that through call centres or online services – are accessible for people with dementia. Shopping and using services were covered in both the survey and interviews and more broadly throughout the research, as both an activity that people with dementia continued to engage in but also as one that as their dementia progressed, people had had to give up on. Some people who were interviewed identified a particular fear and worry that they might leave a shop without paying.

Consideration needs to be given to changing technology and its impact on people with dementia. For instance, supermarket or library self-service checkouts are increasingly common. These can act as a barrier for people with dementia being able to complete everyday tasks independently (Brorsson et al, 2011; Innovations in Dementia, 2011). Further, activities that involve managing finances, paying bills or have security requirements can prove problematic for people with dementia.

Shops, business and services in a dementia-friendly community must therefore have an awareness of dementia and have staff who know how to recognise the symptoms of dementia and particular strategies that can help people with dementia move more efficiently through their business. A starting point for this can be inviting a person with dementia to visit the store and encouraging their comments on their experience, using feedback from a mystery shopper who has dementia or using one of the many environmental checklists that are now available, such as the those compiled by Hampshire County Council (available at www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-toolkit.htm)

Where is this working?

Bradford – The Co-operative and Lloyds TSB

Bradford made an early start on its dementia-friendly work, with the local Alzheimer's Society having helped to set up partnerships between local organisations, businesses and counsellors in 2011.

Local businesses Lloyds TSB and The Co-operative, are just two examples of those taking up the cause to become dementia friendly. Mystery shoppers have helped to reveal what people with dementia need to make everyday tasks that little bit easier. Both business have provided staff training in dementia and are looking to further improve services with feedback from people with dementia.

For Lloyds TSB, this is also about making the connection between its national and local dementia-friendly commitments. Nationally, Lloyds TSB is leading work on dementia-friendly protocol for the finance sector. Locally in Bradford, time has been made to discuss vulnerable clients in team meetings, a quiet space is offered to people who are confused, and signage has been improved.

Future support has been secured from the Joseph Rowntree Foundation and Bradford Council to take this work forward. Over the next two years work will be progressed with 20 communities, building on the Bradford Dementia Action Alliance and working across the four council area committees, to ensure representation of people with dementia and build best practice.

Dementia-friendly hairdressers

As part of creating a dementia-friendly Crawley, one of the local colleges that provides courses in hair and beauty has started offering treatments specifically for people with dementia. The positive outcomes are two-fold: firstly as an intergenerational project that builds awareness in young people in training who will probably have older people as their customers; and also ensuring that people with dementia can continue to access a service that they have identified as important to them.

6.7 The physical environment and public spaces

There is strong and growing evidence to show that people with dementia benefit from engaging in outdoor spaces, in terms of enjoyment, health and quality-of-life outcomes. Qualities identified in the research on age-friendly communities suggest that physical environments need to be clean and pleasant; have spaces for rest, attention to green space and pedestrian activity; have appropriate pavements; and feel secure, accessible and safe to users (World Health Organization, 2007).

Of particular relevance to people with dementia, the Lifetime Neighbourhood programme (Bevan and Croucher, 2011) identified the importance of creating walkable environments to ensure the most inclusive use of public space for as many people as possible. Factors that contribute to help people find their way include rest points, seats and benches, clear signage and accessible toilets.

People with dementia wish to preserve a sense of continuity in their daily tasks and will need more support to do so as time goes on. To continue using public spaces independently, people with dementia value familiarity both in terms of place and activity (Brorsson et al, 2011). This reinforces the role that befrienders can play in helping people with dementia maintain outdoor activities.

The importance of the physical and built environment should not be underestimated in the development of dementia-friendly communities. New and existing development and planning projects should be considered from the lens of people with dementia to ensure spaces are accessible and inclusive.

Where is this working?

Neighbourhoods for Life

This study, carried out by Oxford Brookes University, aimed to find out how to create dementia-friendly neighbourhoods which enable people with dementia to participate in their local communities. This research involved 45 people with dementia aged over 65 who still use the outdoor environment.

First of all, researchers spoke to the people with dementia about their experiences and then observed them on a walk in their neighbourhood. The findings show that there are six major requirements for outdoor environments to be dementia friendly: they need to be familiar, distinctive, accessible, comfortable, safe and have legible signage.

From this, Neighbourhoods for Life have produced a checklist of characteristics of dementia-friendly neighbourhoods. This lists the priorities for people with dementia in terms of accessibility in their local community. In fact, incorporating the characteristics of dementia-friendly environments into inclusive urban design improves the quality of life for all people living in the area and not just people with dementia.

Greening Dementia

Greening Dementia brings together Dementia Adventure, Natural England and the Woodland Trust. This partnership is collecting evidence to better understand how engagement with the natural environment can benefit those living with dementia and to develop project proposals that test a number of large-scale interventions to improve access to the natural environment for people with dementia.

Architects and design

Pozzoni Architects adopt dementia-friendly design principles in their buildings to ensure that the built environment is clear, easily understood and legible for people with dementia. Some of these principles include creating landmarks for orientation and navigation, ensuring reception areas or shop checkout areas can be easily seen, good levels of lighting, minimal background noise, contrast between floor and wall surfaces, and ensuring public toilets are easy to find. Ideally a quiet area where someone who is agitated can calm down should be provided.

Local authority planning departments, property developers and architects all have a role to play in ensuring that new building developments are dementia friendly and existing buildings and streets can be adapted to become more dementia friendly.

King's Fund – Enhancing the Healing Environment programme

The King's Fund has been working to improve the care environment for people with dementia in hospital.

Funded by the Department of Health, the Enhancing the Healing Environment programme involved 23 teams from acute, community and mental health NHS trusts. Projects centred around making hospital environments less alienating for people with cognitive problems.

Projects have shown how relatively inexpensive interventions, such as changes to lighting, floor coverings and improved navigation, can have a big impact. Evaluation has shown that these environmental improvements can also help reduce falls, violent and aggressive behaviours, and improve staff recruitment and retention.

The King's Fund has produced resources to enable care environments, including hospitals and care homes, to become more dementia friendly. (See www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia)

6.8 Further examples of organisations and communities becoming dementia friendly

6.8.1 Plymouth

Taking an operational and strong action focus, Plymouth's local Dementia Action Alliance is well on the way to making its community more dementia friendly.

Local research found that the people with dementia needed help to make everyday tasks easier and 'that the vast majority of businesses, agencies and people in Plymouth had no perception of what life is like for individuals with dementia and their carers'.

Chaired by the Lord Mayor of Plymouth, the Plymouth Dementia Action Alliance (PDAA) members include:

- **Plymouth Naval Base:** The Naval Base in Plymouth was one of the first signatories to the Dementia Action Alliance. Since then the PDAA has provided awareness sessions for members of Naval Families Service and Naval Base staff to raise awareness of the difficulties some of their staff face in maintaining caring duties alongside their work responsibilities. HR policies now reflect the needs of carers within the workforce and Naval Personal and Family Service (NPFs) have made it a priority to ensure that servicemen and women deployed on tours of duty are assured that their loved ones in need of care will be given the support that they require.
- **Dartmoor Rescue Team:** The team at Dartmoor have not only developed a highly sophisticated method of tracking the whereabouts of people with dementia who walk about, but also they have employed their services in providing guided walks for people with dementia and their family carers.

- **Plymouth City Council:** Plymouth City Council is implementing staff dementia awareness training and introduced a Dementia Quality Mark for all providers of residential care who wish to contract with the council's social care commissioners.
- **Plymouth Raiders Basketball Team:** The Raiders, who produce a weekly match programme, have dedicated one full page each week about dementia. This will reach their entire fan base.
- **Plymouth City Centre Manager:** The City Centre Manager committed to implementing a dementia awareness programme for all 400 retail outlets in the city centre.

6.8.2 Crawley, West Sussex

Grant funding from the Prime Minister's Dementia Challenge Fund is helping Crawley Dementia Alliance reach out to new networks and make Crawley a dementia-friendly community. Bringing together a range of players across government, health, business and community, this local Alliance aims to make Crawley 'a town where the people living with dementia and their families are able to live well and are supported across the town to get the help they need to ensure everyday life and pursuit of leisure and cultural activities are made easy'.

The Alliance has taken a 'just get on with it' attitude towards new projects and ideas for becoming dementia friendly. It has launched a range of training opportunities, events and neighbourhood programmes and also started the 'Forward Thinking' group, which brings together people with dementia to find out their experiences and aspirations for the community. There has been outstanding commitment from participating organisations, from fire services to local colleges. Malcolm Bray, Chair of the Crawley Dementia Action Alliance said:

'Every meeting we have, people are brimming with ideas and just getting on with things.'

One of the neighbourhood programmes is focusing on breaking down the stigma of dementia often faced in Asian communities. This neighbourhood in particular has the highest-density black, Asian and minority ethnic population in the local area. The local GP surgery is leading the work and encouraging its partners and staff to be a part of the social movement to become dementia friendly. The programme aims to build awareness throughout local businesses around the neighbourhood centre.

6.8.3 The Debenham Project, Suffolk

The Debenham Project, based in Debenham and its surrounding villages, recognises that dementia is not just a national problem. It is personal, and support for people with dementia must be provided locally and supported by the community – '7, 12, 14 miles is too far to travel for services'.

The project developed after a community meeting where there was agreement that 'we should just get on and do something' for people with dementia and their carers. The project is now up and running and offers a comprehensive set of volunteer-based dementia services to the local area. Latest activities have included new dementia training sessions for individuals and organisations; and the 'Debenham On-Call' project which provides trained volunteer carers to stand-in in emergency and other critical situations.

6.8.4 Dementia-friendly villages: Idle and Girdlington, West Yorkshire

Idle is moving towards becoming a dementia-friendly village. Following a community meeting, a group of active volunteers pulled together to form an action group. In its first meeting people were asked to identify what was working well in their village, what could be done better, and what they were prepared to do to help make Idle dementia friendly.

Early ideas for action included organising transport for shopping and then following this up with a lunch or a coffee in a local café. Another idea suggested forming a memories or reminiscence group that would suit not only people with dementia, but other older people or those feeling lonely or isolated from their community.

There has been strong buy-in to the project from the Council Ward Officer, faith groups and businesses. So much so, that the dementia-friendly message is spreading to other nearby villages and towns. Less than five miles down the road, the village of Girdlington is now exploring how it too can become dementia friendly. Girdlington has a high South Asian population, so while ideas from Idle are being adapted to suit, they are also looking at bilingual services to get more people involved. Work has commenced between the Alzheimer's Society, the Mosque and Meri Yaadain, a specific South Asian dementia service.

6.8.5 Dementia-supportive communities, Brecon, Wales

In Brecon town, and the surrounding area, there has been a grassroots approach to the Dementia Supportive Communities initiative.

In June 2013, volunteers from a local community organised a meeting with Alzheimer's Society and Brecon Town Council. Over 30 representatives from the health and social care, community, voluntary, public and independent sectors, as well as carers and individuals, came together to find out more about dementia-supportive communities.

A community-led steering group, including the former Brecon Mayor has been established and is working closely with the Alzheimer's Society co-ordinated Brecknockshire Dementia Action Group.

6.8.6 Creating a dementia-supportive community in Swansea, Wales

The first meeting of the Swansea Dementia Supportive Community Forum brought together diverse representatives from Alzheimer's Society, local solicitors, care home providers, councillors, South Wales Police, Swansea Business Improvement District, All Wales Academic Social Care Research Collaboration and Age Cymru. The aim of the Forum is to improve the lives of those in Swansea who are living with dementia and their carers.

The vision for Swansea is to become a city where all businesses and staff are aware of the needs of people with dementia so that everyone can continue to live fulfilling lives, doing what they have always done. This could include support for day-to-day activities such as going out for coffee, working, having a social life, and enjoying hobbies and sports.

Key commitments being explored include:

- all businesses committing to make at least one employee a dementia champion for their organisation
- general public dementia awareness training sessions to increase daily support available from friends, people in the street, and to promote a feeling of social inclusion rather than the isolation that is currently prevalent
- professional bodies listening to how people with dementia are feeling
- improving the use of advocacy services and legal support for people to make their own informed decisions.

6.8.7 Dementia-friendly Northern Ireland

Funded by Atlantic Philanthropies, Northern Ireland started its dementia-friendly communities programme in 2013. Already in these early stages, commitment to the initiative has been strong. Of the 26 local councils, 25 have signed up to becoming dementia friendly and will be using their networks from staff, voluntary, community and business sectors to improve awareness of dementia and drive change in the community.

In partnership with others, Alzheimer's Society will deliver interactive dementia awareness workshops, provide support to organisations to ensure human resource policies support people living with dementia, and drive a media campaign. A further project involves pushing for a business quality mark to include a standard for dementia. The aim is to drive better customer service, ensuring that businesses throughout the area have an awareness of dementia and are able to support those living with the condition and their carers.

Alzheimer's Society has held two dementia awareness workshops in Coleraine. From this, seven new volunteers have been recruited and will be trained to deliver awareness-raising workshops in future.

6.8.8 Dementia-friendly Surrey

Surrey County Council and three of Surrey's clinical commissioning groups have embarked on a project to support communities across Surrey to become more inclusive and supportive places for people with dementia and their families. A number of ideas have been generated since the launch – from dementia-friendly parking at the supermarket to supporting people with dementia to volunteer in their community.

Dementia-friendly champions are currently touring high streets to drum up interest in the project; the response has been encouraging with cafés, hairdressers, supermarkets, and other retailers willing to get involved.

6.8.9 Including people with dementia – shaping generic services, Age UK

Age UK is testing new ways to make 15 of their local services across England more inclusive of people living with dementia. Funded by the Department of Health Strategic Partners programme, the ‘Including people with dementia – shaping generic services’ programme is working to engage with people with dementia and their carers.

Innovative projects, training and awareness raising activities are happening across the sites, but to cite a few:

- Age UK Calderdale and Kirklees found that the newly diagnosed people in their community often experienced feelings of bewilderment, fear and being ‘banned from everyday life’. A group of ten Dementia Buddies are working to help offer people with dementia more than ‘just day centres’ to keep out and about in their community. New activities are being organised for people based on what they enjoy and like.
- In Isle of Wight, the local Age UK recognises that becoming dementia friendly will bring immediate benefits to its organisation and customer relations but, in the long run, will also help people with dementia stay in their own homes for longer; and avoid unnecessary stress and crisis points. On the path to becoming dementia friendly, they are offering cross training with public sector organisations, such as the police, fire service and local authority. Future projects include looking at how to work more with partners in the Dementia Action Alliance.
- Aiming to ensure that no one is uncomfortable, frightened or embarrassed when it comes to dealing with people who are living with dementia, Age UK Blackpool will roll out a new mandatory training package for all staff and volunteers. Working with people with dementia and their carers to develop the training, they can see a good opportunity to extend this to local retailers and community members to raise awareness of dementia.

6.8.10 Innovations in Dementia

Innovations in Dementia works nationally with people with dementia, partner organisations and professionals to develop and test projects that will enhance the lives of people with dementia. Projects are designed to show what people with dementia have to offer, underlined by the belief that while a diagnosis of dementia might be life-changing it need not be life-ending.

Since 2011, Innovations in Dementia has been working on dementia-friendly communities, in partnership with Local Government Group, Department of Health, Joseph Rowntree Foundation, and Alzheimer’s Ireland.

One of its most widely adapted projects, Developing dementia-friendly communities: learning and guidance for local authorities, worked with Sheffield City Council and Hampshire County Council to explore what developing a dementia-friendly community meant for local government and practical ways to make a start. More recently, Innovations in Dementia has been working with Age UK to support its mainstream services becoming more accessible to people with dementia.

Ultimately, Innovations in Dementia wants to encourage and foster a different narrative about dementia: to work with people with dementia in ways that support them to develop a vision for living well with dementia, and promote the sense that they have a right to a say in the decisions that affect their lives.

6.8.11 Joseph Rowntree Foundation – York

Joseph Rowntree Foundation (JRF) is supporting the dementia-friendly movement in the Yorkshire region (particularly in York and Bradford) and across the UK.

JRF wrapped up the first phase of its Dementia Empowerment and Engagement Project (DEEP) in summer 2012. Over the next three years, the JRF will invest in supporting the growth of a stronger collective voice of people with dementia across the UK.

JRF is now looking to invest in evidence-building in Wales, Northern Ireland and Scotland, through a new project on dementia-friendly communities. It is intended to generate rich case studies, fund evaluations and stimulate local action. It is particularly interested in projects that include a focus on equality and diversity, poverty and place (including rural/urban).

JRF is part of the Yorkshire and Humberside Dementia Action Alliance (YHDAA); national Dementia Action Alliance; and the national DFC Champions Group.

Members of the YHDAA are working on a number of community projects and initiatives in York including the following:

- British Transport Police has helped to re-familiarise people with dementia with process at the station such as how to buy tickets and board a train. They are also encouraging more people to use trains to get out and about.
- Energise Leisure Centre has demonstrated how local people with dementia and their carers can play adapted sports and activities such as 'Jiminy Wicket' (a simplified form of croquet). A new course is under development, with Sports Coach UK, to help all sports and leisure clubs in York to become dementia friendly.
- City of York Council and the Primary Care Trust have jointly funded Dementia Forward to help with community development in York.
- Senior drama pupils at Joseph Rowntree School spent time with a person with dementia and his wife to deepen their understanding of how they see the world, before developing a piece of theatre which they performed at the Annual General Meeting.
- GeniUS! York launched its ground-breaking Dementia without Walls Challenge – a chance for the people of York to bring all their expertise together to find solutions to some of the practical challenges people with dementia face in their daily lives. The winning bid focuses on designing assemblies on dementia for all local schools. One of the judges was a person with dementia.
- JRF has introduced a new grants stream for local dementia-friendly ideas. People with dementia are involved in assessing the proposals and four projects are starting up.

- York Art Gallery has hosted arts and crafts sessions.
- JRF and Joseph Rowntree Housing Trust are also committed to becoming dementia-friendly employers.
- A new network (York Dementia Action Alliance) is being established with local partners.

In Bradford, JRF is providing joint funding with Alzheimer's Society to continue the work on dementia-friendly issues.

6.8.12 AESOP Consortium

The AESOP Consortium has been funded to develop an accelerated learning programme in Doncaster, and Redcar and Cleveland. Both areas are well aware of the need to become dementia friendly and want to improve their responses to people with dementia.

Doncaster in particular has progressed well, partly due to the drive of Council leaders. Workshops using an approach developed by the Joseph Rowntree Foundation have been successful in uniting statutory, commercial, voluntary and other diverse communities. Doncaster is now well positioned to continue building on the dementia-friendly agenda, ensuring that people who have dementia, their families and carers are supported to live well.

In Redcar and Cleveland, there is great willingness, with some fantastic ideas coming out of local enthusiasts. Learnings from the programme so far will benefit the next round of workshops and site visits.

6.8.13 Pass on the Memories – Everton in the Community and Mersey Care NHS Trust

Everton in the Community and Mersey Care NHS Trust have launched an innovative new programme to support people with dementia.

The Blues' official charity and Mersey Care have developed a unique initiative, known as Pass on the Memories, for patients with memory loss. The weekly scheme uses a range of interventions, including sporting reminiscence workshops, custom-made life story memory books and calendars, day trips to local places of interest and social activities, to help people to share important memories and create new ones.

One particular tool used in the sessions is an audio CD containing interviews and stories from past Everton players, including Dixie Dean and Graeme Sharp.

Everton in the Community and Mersey Care are supporting Liverpool PCT and Liverpool City Council's Year of Dementia Awareness campaign. The campaign aims to develop understanding and awareness of dementia and work towards creating dementia-friendly environments in work places, public areas and communities, with Pass on the Memories being just one initiative to help achieve these goals.

Everton hopes that other clubs will follow its lead and a similar programme is already being developed for North Sefton residents to be hosted at Southport Football Club.

The Sporting Memories Network was instrumental in helping to develop the sporting reminiscence resources and expertise that are utilised in the Pass on the Memories dementia programme, following its pioneering work in Scotland.

6.8.14 The Museum of Liverpool – House of Memories

The House of Memories offers unique and innovative training to help people living with dementia. It gives people in Merseyside working in sectors supporting those living with dementia the opportunity to take part in practical and interactive training in a museum setting.

Using a setting in the heart of the community, the House of Memories offers a toolkit to carers, which is based on the varied array of objects, archives and stories at the Museum of Liverpool. The training gives carers the skills to inform their practice and the resources to carry out memory activities in work settings, and improve quality of life for people living with dementia.

Professor Phil Redmond CBE, Chairman of National Museums Liverpool said:

‘The House of Memories shows the value of the cultural sector working effectively with the health and social care sector to tackle society’s understanding of dementia. It’s an opportunity to get people thinking differently, and by understanding the benefits of cultural engagement, people can use art and culture to improve both their work and the lives of those living with dementia.’

National Museums Liverpool piloted the scheme early in 2012 with the local dementia community and more than 1,200 health and social carers took part. An independent evaluation of the project revealed it had a profound impact on participants, increasing their awareness and understanding of dementia and helping them to understand those living with the condition.

Those who took part were encouraged to explore the collections of the Museum of Liverpool and to learn how to positively engage and communicate with people living with dementia, by using objects and memorabilia from the Museum which were relevant to people’s personal histories.

The training, which will continue this autumn, is practical and interactive, partnering with AFTA Thought training consultants, who use drama to present factual information about dementia and help participants to understand the experience of living with dementia, whether a family carer or care worker. The Museum has also developed memory box and memory walk sessions to help participants integrate the training and new resources into their day-to-day interactions with people living with dementia.

More information is available at www.liverpoolmuseums.org.uk/houseofmemories

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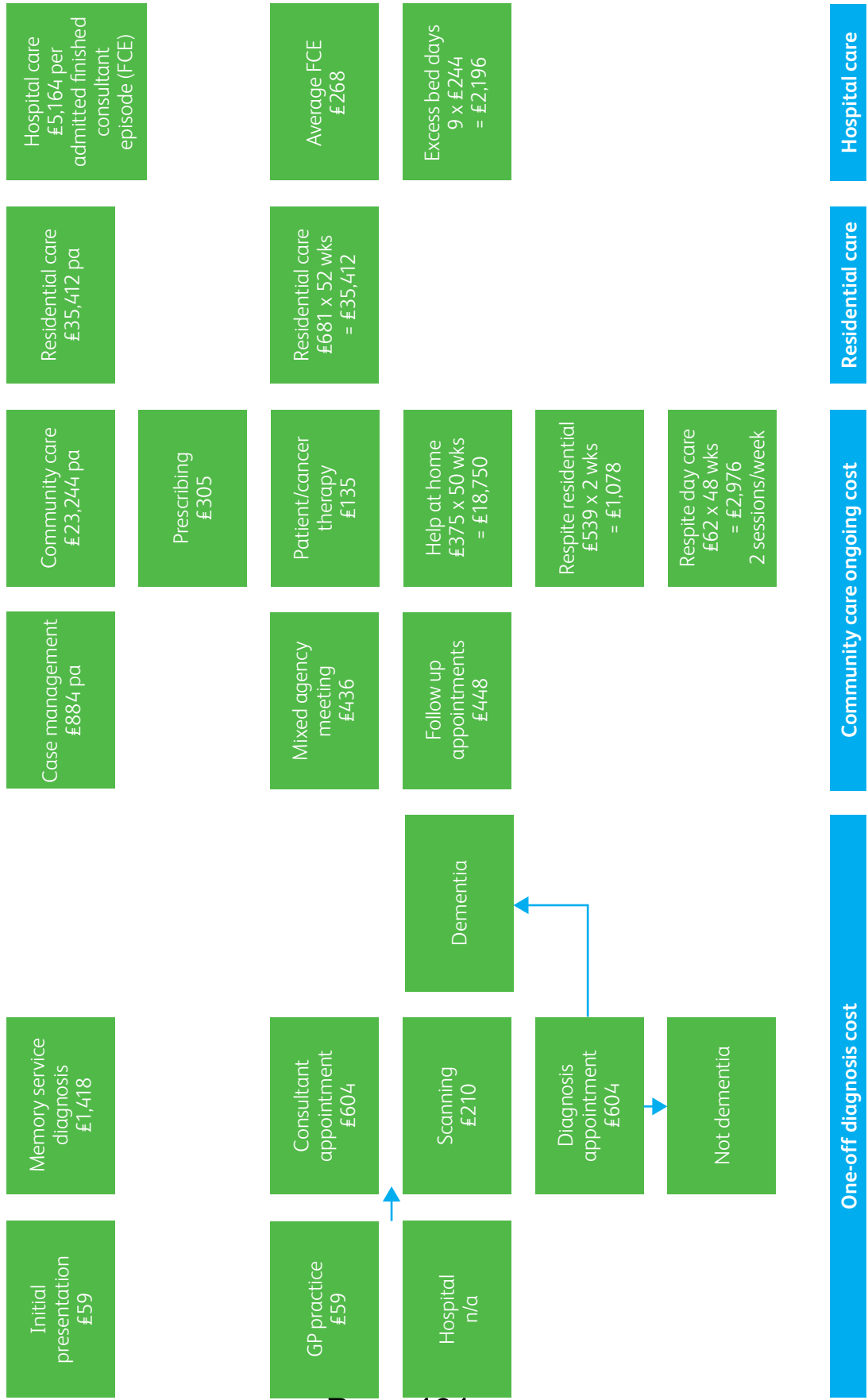
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Appendix A: Economic case

Estimating the costs per diagnosed person within the dementia pathway



Appendix B: Dementia Action Alliance members

The 121 national members of the Dementia Action Alliance:

360 Forward
 Aesop Consortium
 Age Related Diseases and Health Trust
 Age UK
 Age Watch
 All-Party Parliamentary Group on Dementia
 Alzheimer's Research UK
 Alzheimer's Society
 Anchor
 Architectonicus
 Arts4Dementia
 Association for Dementia Studies, University of Worcester
 Association of British Neurologists
 Association of Directors of Adult Social Services
 Barchester Healthcare
 Bradford Dementia Group, University of Bradford
 British Association for Counselling and Psychotherapy
 British Association of Occupational Therapists and College of Occupational Therapists
 British Geriatrics Society
 British Psychological Society
 BSI
 BT
 Bupa
 Care Quality Commission
 Care UK
 Carers Trust
 Chartered Society of Physiotherapy
 Clairmont PLC
 Country Cousins
 Dementia Adventure
 Dementia Advocacy Network
 Dementia Services Development Centre
 Dementia UK
 Dementia web supported by Guideposts Trust
 Dementias & Neurodegenerative Diseases Research Network (DeNDRoN)
 Department of Health
 Design Council
 Direct Marketing Association
 English Community Care Association (ECCA)
 Excelcare
 ExtraCare
 Find

FinerDay
Four Seasons Health Care
Guinness Care and Support
Hallmark Care Homes
Hawker Publications
HFT
Housing 21
Housing and Dementia Research Consortium
Housing LIN
Independent Age
Innovations in Dementia
International Longevity Centre UK
Jewish Care
Joseph Rowntree Foundation/ Joseph Rowntree Housing Trust
Journal of Dementia Care
Kim Grove Garden Designer
Kings Health Partners Academic Health Sciences Centre
Lewy Body Society
Lilly UK
Lloyds pharmacy
Local Government Association
Lost Chord
Lundbeck
Memories UK
Mental Health Foundation
MHA
My Amego Healthcare Limited
My Life Software
NAPA (National Association for Providers of Activities for Older People)
National Care forum (NCF)
National Council for Palliative Care and Dying Coalition
National Development Team for Inclusion (NDTi)
National Housing Federation
National Institute for Health & Clinical Excellence
National Skills Academy for Social Care
NHS Alliance
NHSConfederation
Norfolk and Suffolk Dementia Alliance
Nutricia
Parkinson's UK
PayingForCare
Pictures to Share C.I.C.
Pintrack Ltd
Pozzoni LLP Architects
Prestige Nursing + Care
Priory Group
Radcliffe & Speechmark Publishing
Re:Cognition Health Ltd
Rotarians Easing Problems of Dementia
Royal College of General Practitioners
Royal College of Nursing

Royal College of Physicians
Royal College of Psychiatrists
Royal Pharmaceutical Society
Royal Voluntary Service
Saga Homecare
Shared Lives Plus
Skills for Care
Skills for Health
Social Care Institute for Excellence
Social Care Workforce Research Unit, King's College London
Southern Healthcare
The Alzheimer's Show
The Good Care Group
The Life Story Network CIC
The Orders of St John Care Trust (OSJCT)
The Retreat
The Stroke Association
The Woodland Trust Visit Woods Project
Thomas Pocklington Trust
Three Minute Trainer
Tim Lynch Associates
Towergate Financial
trueCall Ltd
United Kingdom Homecare Association (UKHCA)
Visioncall
Vitalise
Yecco
YoungDementia UK

Notes

Notes

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit alzheimers.org.uk or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 11 22** (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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