

Making Southampton Dementia Friendly Scrutiny Inquiry Panel

Dementia-friendly communities



PANEL MEMBERSHIP

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SOUTHAMPTON
CITY COUNCIL

Contents

Contents	Page
Chair's Introduction	3
The Aim of the Inquiry	4
Introduction	6
Conclusions and Recommendations	11

Appendices

Appendix 1 – Terms of Reference

Appendix 2 – Inquiry Plan

Appendix 3 - Summary of Key Evidence

Appendix 4 – Findings

Appendix 5 - Types of Dementia

Chair's Introduction



**Councillor Hannah Coombs - Chair of the Making
Southampton Dementia Friendly Inquiry Panel (2015/16)**

To be added for 16 June meeting of the Overview and Scrutiny
Management Committee

Making Southampton Dementia Friendly

The Aim of the Inquiry

1. In March 2012 the Department of Health published the Prime Ministers Challenge to deliver major improvements in dementia care and research by 2015.
2. In February 2015 the Department of Health, building on the Challenge published in 2012, published the Prime Ministers Challenge on Dementia 2020 which sets out the programme of action to deliver sustained improvements in health and care and boost dementia research.
3. In acknowledgement that two thirds of people with dementia live in the community¹ a key objective within the 2020 Challenge includes:
 - Over half of people living in areas that are recognised as Dementia Friendly Communities.
4. 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.'*²
5. In recognition of the importance of this issue, and the opportunity to make a difference for people living with dementia and their carers in Southampton, the Overview and Scrutiny Management Committee (OSMC), at its meeting on 13th August 2015, requested that the Scrutiny Inquiry Panel undertake an inquiry looking at how Southampton can become a dementia friendly city.
6. The OSMC agreed that the inquiry would not focus on the wider issues of prevention, research, or clinical treatments for people with dementia.
7. The set objectives of the Inquiry were:
 - 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.
8. The full terms of reference for the Inquiry, agreed by the OSMC, are shown in Appendix 1.

¹ Dementia UK, Second Edition - Overview, Alzheimer's Society, September 2014

² Alzheimer's Society, Guidance for communities registering for the recognition process for dementia friendly communities, 2013

How the inquiry was conducted

9. The Scrutiny Inquiry Panel undertook the inquiry over 6 evidence gathering meetings and received information from a wide variety of organisations. This included health professionals, charitable organisations supporting people with dementia, volunteers, housing managers, urban designers, shopping centre operators, commissioners, academics and bus operators. A list of witnesses that provided evidence to the Inquiry is detailed in Appendix 2.
10. To deliver the set objectives the agreed project plan identified that each evidence gathering meeting of the inquiry would focus on a number of the 10 key characteristics of a dementia friendly community.
11. At each meeting appropriate guests were invited to outline activities and practice in Southampton related to the 10 key areas and to identify what best practice looks like. This enabled the Panel to undertake a mini audit of the strengths and weaknesses/opportunities in the city and to recommend key actions that, if implemented, would help Southampton become more dementia friendly.
12. In undertaking this inquiry the Panel were made aware that the development of dementia friendly communities was a cross cutting issue and that councils, working in partnership with others, are well placed to deliver on this ambition.
13. The key findings, conclusions and recommendations from the inquiry are detailed succinctly later in this report.

Consultation

14. 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. In recognition of this principle from the outset the inquiry has sought to engage people with dementia and their carers. In addition to Panel Members attending a Dementia Friends Awareness session specific events designed to engage and understand the views of people with dementia in Southampton include:
 - A visit to the Memory Café at Medwall Court – 6th October 2015
 - A visit to Dementia Friendly Fridays at Manston Court – 12th February 2016.
15. Members of the Panel would like to thank all those who have assisted with the development of this review, in particular Amanda Luker, Commissioner within the Integrated Commissioning Unit, who has provided the Panel with invaluable advice throughout the inquiry.

Introduction

What is Dementia?

16. The word 'dementia' describes a group of symptoms that include loss of memory, difficulties with planning, problem solving, difficulties with language and communication, and sometimes, changes in mood or behaviour.
17. Dementia isn't a natural part of aging. It occurs when the brain is affected by a disease. Dementia is progressive, which means the symptoms will gradually get worse over time.

Types of Dementia

18. There are many types of dementia but the most common are Alzheimer's disease and vascular dementia. Of those people with dementia in the UK, 62% have Alzheimer's disease and 17% vascular dementia. Others include mixed dementia (10%), dementia with Lewy bodies (4%), rarer causes of dementia (3%) and fronto-temporal dementia (2%). Appendix 5 provides a brief description of each type of dementia.

Facts and Figures

19. In England, it is estimated that 676,000 people have dementia³. It is expected that this figure will double in the next 30 years as life expectancy increases.
20. Dementia costs society an estimated £26 billion a year, more than the costs of cancer, heart disease or stroke. In the next 30 years, predicted costs are likely to treble⁴.
21. The estimated number of people with dementia in Southampton is 2,618 (March 2015). This figure is expected to rise in line with an increase in the over 65 population which is expected to grow by 11% between 2012 and 2019.

What are Dementia Friendly Communities?

22. Traditionally, the focus for dementia care has been NHS treatments and care services delivered by local councils. Recently there has been a shift to a focus on how we can enable people who have been diagnosed with dementia to live as full a life as possible and encourage communities to work together to help people to stay healthier for longer.
23. Alzheimer's Society have been active in the move nationally towards supporting communities to become dementia friendly. They define a dementia-friendly community as 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.⁵
24. A number of communities have already signed up to the national Dementia Friendly Communities accreditation process, overseen by Alzheimer's

³ Department of Health, Prime Minister's challenge on dementia 2020, February 2015, p10

⁴ Department of Health, Prime Minister's challenge on dementia 2020, February 2015

⁵ Alzheimer's Society, Building dementia-friendly communities: a priority for everyone, August 2013

Society, and are making progress supporting people with dementia to live well with the condition.

Why is it important that communities become dementia friendly?

25. People with dementia want to live everyday lives continuing to stay connected to their interests, social networks and communities. However, research suggests that people with dementia increasingly withdraw from everyday life.⁶
26. Two thirds of people with dementia live in the community, close to a third of whom live on their own. With the support from wider communities, enabling people with dementia to take part in everyday activities is key not only to enabling them to live fulfilling lives but to reducing and delaying their dependence on expensive health and social care services.⁷
27. Dementia has a significant financial impact. Analysis shows that a year living in the community with dementia is estimated to cost £24,128, including integrated health and social care package, together with respite, therapies and medication. A year in residential care costs an average of £35,424. Therefore a saving of £11,296.⁸ The more support we can give people with dementia to remain independent within communities the better for the individual and the greater the savings on public finances.

What are the key characteristics of a dementia friendly community?

28. In 2013 Alzheimer's Society and the National Dementia Action Alliance identified 10 key areas that communities working to become dementia friendly should focus on:

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.

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.

⁶ Alzheimer's Society, Building dementia-friendly communities: a priority for everyone, August 2013

⁷ LGA, Dementia Friendly Communities – Guidance for councils, July 2015

⁸ Alzheimer's Society, Building dementia-friendly communities: a priority for everyone, August 2013

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.

What is the process to become accredited as a dementia friendly community?

29. The journey to become a dementia-friendly community will take time and Alzheimer's Society are currently reviewing the assessment process. To become part of the current dementia friendly communities recognition process, a representative from a community needs to fill out an online application form. By registering for the process your community commits to, amongst others, the following conditions:
 - Meeting the foundation criteria for a dementia-friendly community that have been developed
 - Providing a brief six-monthly update
 - Completing an annual self-assessment of progress towards the criteria.
30. Once a community has registered with the process, they may demonstrate how they meet the foundation criteria for 'working to become dementia friendly' by:
 - Ensuring the right local structure is in place to maintain a sustainable dementia friendly community

- Identifying a person to take responsibility for driving forward the work to support a community to become dementia friendly
- Having a plan in place to raise awareness about dementia in key organisations and businesses within the community that support people with dementia
- Developing a strong voice for people with dementia living in communities
- Raising the profile of the work to increase reach and awareness to different groups in the community
- Focusing plans on a number of key areas that have been identified locally
- Having in place a plan or system to update the progress of your community.



31. Once a community has demonstrated how they meet the criteria, they are issued with a symbol that they can give to organisations and businesses in their community that wish to be part of the dementia friendly communities' initiative and have stated what their actions are towards becoming dementia friendly.
32. The process is designed to enable communities to be publicly recognised for working towards becoming dementia friendly and to show that they are following common criteria that are based on what is known to be important to people affected by dementia and will change their experience.
33. At the time of the presentation to the Panel 115 communities had registered through the Alzheimer's Society Dementia Friendly Communities recognition process. In recognition that becoming a dementia friendly community may take a number of years the Panel, at the meeting on 29th October 2015 recommended that officers submit an application as soon as possible for Southampton to be recognised as 'working towards becoming dementia friendly' to formally start the journey.

Dementia Friends and Dementia Action Alliances

34. Dementia Friends, Dementia Champions and Dementia Action Alliances are important enablers to creating dementia friendly communities. Dementia Friends is a national initiative to raise awareness of dementia. There are 1.3 million Dementia Friends nationally who are able to recognise the symptoms and support people with dementia, with a target for a further 3 million by 2020.
35. Dementia Friends awareness sessions are delivered by Dementia Champions. To become a Dementia Friends Champion, a person must attend a one day course run by Alzheimer's Society.
36. A Dementia Action Alliance is a steering group of local stakeholders working with organisations and businesses to support and encourage them to take actions to work to become dementia friendly. To become a member organisations must sign up to the National Dementia Declaration and submit a short action plan setting out how they will work towards delivering the outcomes outlined in their declaration.

37. In September 2015 there were 170 Local Dementia Action Alliances nationwide. They are recommended vehicles for developing dementia friendly communities. Hampshire is recognised as being in the vanguard in developing dementia friendly communities and has an active Dementia Action Alliance that works under the umbrella of the Dementia Friendly Hampshire project, established in 2013 and managed by Andover Mind. Southampton has a Dementia Partnership but not a Dementia Action Alliance.

Conclusions and Recommendations

38. A summary of the key evidence presented at each of the inquiry meetings is attached as Appendix 3. In addition a summary of findings for Southampton against the key areas of focus for communities working to become dementia friendly is attached as Appendix 4. Conclusions were drawn from each meeting and disseminated to the Panel. All of the reports, presentations and minutes from the inquiry meetings can be found here:

<http://www.southampton.gov.uk/modernGov/ieListMeetings.aspx?CommitteeId=624>

Conclusions

- The inquiry has clearly demonstrated to the Panel that people can live well with dementia and that there are significant benefits to individuals living with dementia and the City of Southampton in becoming dementia friendly.
- The Panel were encouraged by the range and diversity of activities and support currently being provided to people with dementia and their carers across Southampton.
- The Panel recognised that there had been substantial improvements in the support to people with dementia and their carers in the city over the past few years, particularly in the integration of housing, health and social care services, and the increasing diagnosis rates, and that outcomes would continue to improve.
- However, Southampton can do more to support people with dementia and changes can be made that can make the day to day lives of people living with dementia and their carers better.
- Examples of good practice exist locally that Southampton can learn from as we seek to become dementia friendly. Hampshire has demonstrated what can be achieved with focus, planning and support.
- To help the city to become dementia friendly a priority must be to improve co-ordination. This will help spread good practice across Southampton and galvanise community support.
- To help achieve this priority the Panel, at the second meeting of the inquiry, recommended that the Integrated Commissioning Unit utilise an identified budget for 2015/16 to commence a procurement process to engage an organisation to oversee and kickstart the drive to becoming dementia friendly. This has proved invaluable in Hampshire.
- It is identified good practice that a Southampton Dementia Action Alliance is established to work alongside the aforementioned organisation procured to kickstart and co-ordinate activity.
- The journey to be recognised as a dementia friendly community should commence as soon as possible with a submission to Alzheimer's Society to be recognised as 'working to become dementia friendly'. The changes will not happen overnight but it is an opportunity to transform the lives of people with dementia and their carers in Southampton.

- It is essential that in order for the drive to become a dementia friendly community to succeed the views and opinions of people with dementia and their carers must be at the heart of any decisions and that consideration should be given to hearing the voice of people with dementia throughout the process.
- The findings and recommendations identified during the inquiry are reflected within Southampton Better Care vision; which is to join up care and support for each and every unique person in our city needing our care. Some of the areas that Better Care contributes to the lives of people living with Dementia specifically in relation to dementia friendly communities includes:
 - Workforce development project that involves organisations within the sphere of better care delivery have a commitment to ensuring that all staff have the skills required to undertake their role
 - The development of cluster teams, providing an integrated approach to care, includes the older person mental health services
 - With the progress of integration, care and support plans will be undertaken in a holistic person centred way
 - Development of cluster working, is resulting in all community providers statutory and non-statutory developing, this will support an increased knowing of where to go for particular resources or support
 - Carer awareness is key to the development of person.

Recommendations

39. Reflecting the key findings and conclusions the following actions are recommended to accelerate progress towards Southampton becoming a dementia friendly city:

General Co-ordination and Strategic Direction

Recommendation 1 - That the Integrated Commissioning Unit engages an organisation to oversee and kickstart the drive to becoming dementia friendly.

Recommendation 2 - That the successful applicant/organisation submits an application to the 'working to become dementia friendly' on behalf of Southampton.

Recommendation 3 - That the Council works with existing members of the Southampton Dementia Partnership to establish a Dementia Action Alliance in Southampton.

Recommendation 4 - That the Council use strategic drivers such as the community safety plan, health and wellbeing strategy, local transport plan, planning function as well as strategies for older people and people with dementia as levers to reinforce the needs of people living with dementia.

Recommendation 5 - That the Council seeks to deliver the recommendations locally identified within the Local Government Associations recently published guide to combating loneliness.

Challenge stigma and build understanding

Recommendation 6 - That Dementia Friends sessions are made compulsory for all customer facing Council employees, including elected members, and that it is included in Council and relevant Capita inductions.

Recommendation 7 - That the Council supports key staff and elected members to become dementia champions – so they can train and support other members and officers to become dementia friends and to act as ambassadors and supporters of work to promote dementia friendly communities locally.

Recommendation 8 - In partnership with the recommended Southampton Dementia Action Alliance a ‘Southampton DEMFEST’ is organised in 2017.

Accessible community activities / Acknowledge potential/ Practical support to enable engagement in community life

Recommendation 9 - With the opening of the new arts centre imminent explore funding opportunities from the Arts Council to facilitate accessible activities for people with dementia.

Recommendation 10 - Explore the opportunity to create a dementia roadmap for Southampton that provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care to support people with dementia, their families and carers.

Community-based solutions

Recommendation 11 - That the City Council’s Housing Services engages with Hampshire Constabulary to utilise new systems to locate people with dementia that have gone missing.

Respectful and responsive businesses and services

Recommendation 12 - Through the Health and Wellbeing Board and NHS Southampton Clinical Commissioning Group General Assembly Southampton GP Practices are actively encouraged to sign up to the ISPACE initiative.

Consistent and reliable travel options

Recommendation 13 - That the Council ensures that new travel and transport schemes in the city incorporate dementia friendly design principles.

Easy-to-navigate environments

Recommendation 14 - That City Council Planning Officers consult groups representing people with dementia in the development of the Local Plan.

Recommendation 15 - That dementia experts at the University of Southampton are invited to give feedback on the Streets and Spaces framework to ensure it reflects the specific needs of people with dementia.

Recommendation 16 - The Council/CCG proactively engages with Hammerson to identify how their resources, enthusiasm and expertise can be utilised to increase support for dementia friendly Southampton.

Recommendation 17 - That office environment audits are undertaken on all City Council customer facing buildings.

Recommendation 18 - That the City Council explores opportunities to develop a Community Toilet Scheme in Southampton.

Appendices

Appendix 1 –Inquiry Terms of Reference

Appendix 2 – Inquiry Plan

Appendix 3 – Summary of Key Evidence

Appendix 4 - Findings

Appendix 5 –Types of Dementia

Appendix 1 – Terms of Reference

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:

- d. To understand how far we are progressing in making Southampton a dementia friendly city, and to identify further actions needed.
- e. To align our work and priorities to the existing framework in place: Alzheimer's Society building dementia-friendly communities - a priority for everyone.
- f. 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.

Appendix 2 - Inquiry Plan

DATE	MEETING THEME	TOPIC DETAIL	EVIDENCE PROVIDED BY
24/09/15	<p>Agree Terms of Reference</p> <p>and</p> <p>Introduction to the Inquiry</p>	Introduction, context and background.	<ul style="list-style-type: none"> • Councillor Shields (Cabinet Member for Health and Social Care) • Penny Ford (Dementia Action Alliances Projects Manager, Alzheimer's Society) • Debbie Morshead (Dementia Friendly Hampshire Project Lead, Andover Mind) • Amanda Luker (Commissioner, Southampton Integrated Commissioning Unit) <p>Items appended to reports:-</p> <ul style="list-style-type: none"> • Inquiry draft Terms of Reference and Inquiry Plan • Building Dementia Friendly Communities: A priority for everyone, Alzheimer's Society
29/10/15	<p>Challenge Stigma</p> <p>Acknowledge Potential</p> <p>Engagement in Community Life</p> <p>Accessible Community Activities</p>	To develop an understanding of the current position in Southampton and best practice.	<ul style="list-style-type: none"> • Sue Dewhirst (Public Health Support Manager, Public Health England) • Sally Denley (Public Health Development Manager, SCC) • Karen Cotton (Lead Admiral Nurse, Solent NHS Trust) • Gary Walker (Services Manager South Hampshire, Alzheimer's Society) <p>Items appended to reports:-</p> <ul style="list-style-type: none"> ○ Feedback from a visit to the Memory Café at Medwall Court ○ Links to Arts Council initiatives

DATE	MEETING THEME	TOPIC DETAIL	EVIDENCE PROVIDED BY
19/11/15	Community Based Solutions	To develop an understanding of the current position in Southampton and best practice.	<ul style="list-style-type: none"> • Dr Rosalind Willis (Lecturer in Gerontology, Centre for Research on Ageing, University of Southampton) • Carol Alstrom (Associate Director of Quality, Integrated Commissioning Unit) • Morag Forrest-Charde (Integrated Care Transformation Manager, Integrated Commissioning Unit) • Nick Cross (Head of Housing Services, SCC) • Jean Brown (Supported Services Manager, SCC)
03/12/15	Respectful and Responsive Business and Services Consistent and Reliable Travel Options	To develop an understanding of the current position in Southampton and best practice.	<ul style="list-style-type: none"> • Phil Williams (Health & Wellbeing Development Officer, Age UK Southampton) • Katherine Barbour (Senior Programme Manager, Wessex Academic Health Science Network & Dementia Friendly Portswood High Street Volunteer) • Paul Walker (Travel and Transport Manager, SCC) • Matt Kitchin (General Manager, Bluestar, Southern Vectis and Unilink, Go South Coast Ltd) • Chrissie Bainbridge (Business Performance Director, First Hampshire, Dorset and Berkshire, General Manager Southampton)
21/01/16	Ensure an Early Diagnosis	To develop an understanding of the current position in Southampton and best practice.	<ul style="list-style-type: none"> • Dr Cliff Howells (Clinical Programme Lead for Mental Health, NHS Southampton Clinical Commissioning Group and Southampton GP) • Dr Maged Swelam (Consultant Psychiatrist, Older People Mental Health, Southern Health NHS Foundation Trust) <p>Items appended to reports:-</p>

DATE	MEETING THEME	TOPIC DETAIL	EVIDENCE PROVIDED BY
			<ul style="list-style-type: none"> ○ Joint declaration on post-diagnosis dementia care and support
25/02/16	Easy to Navigate Environments	To develop an understanding of the current position in Southampton and best practice.	<ul style="list-style-type: none"> ● Dr Ruth Bartlett (Associate Professor in Ageing and Social Research, Faculty of Health Sciences, University of Southampton) ● Darren Shorter (City Design Group Leader, Planning, SCC) ● Jonathan Brookes (Community Manager, Hammerson)
26/04/16	Agree final report.	Approve report for submission to Overview and Scrutiny Management Committee	N/A

The minutes for each meeting, the evidence submitted to the Scrutiny Inquiry Panel and presentations delivered at each meeting is available at: - <http://www.southampton.gov.uk/modernGov/ieListMeetings.aspx?CommitteId=624>

Appendix 3 – Summary of Key Evidence

Scrutiny Panel – Making Southampton Dementia Friendly

Inquiry Meeting 1 – 24 September 2015

Introduction to the inquiry

Summary of information provided:

Cabinet Member for Health and Social Care, SCC – Councillor Shields

- Welcomes the inquiry. Good chance to find out what is going on across the city and to position Southampton as a leading dementia friendly city in Europe.
- Key challenges in the city include: Appropriate mix of housing to support people to live independently; making our town and district centres dementia friendly; equipping public sector staff; understanding the leadership required from the City Council.

Dementia Action Alliances Projects Manager, Alzheimer's Society – Penny Ford

- 850,000 people with dementia in the UK by 2015, predicted to be 2m by 2051
- £26.3 billion per year (£11.6 billion unpaid care)
- 51% carers in work
- Two thirds of people with dementia live in the community. The more support we can give people with dementia to remain independent the better for the individual and the greater the savings on hard pressed public finances.
- A wide range of organisations, all working to become dementia friendly, through awareness raising, reviewing current practices and adapting to meet the needs of people living with dementia.
- Currently 170 Local Dementia Action Alliances: Steering Group of local stakeholders working with organisations and businesses to support and encourage them to take actions to work to become dementia friendly.
- There is a Dementia Friendly Community Assessment and a requirement for a 6 monthly progress update.
- Where should Southampton focus? – Concentrate on a few areas first; more Dementia Friends needed; work with bus companies to make sure people with dementia can get around the city; organise dementia awareness sessions for community groups; improve clarity of signage.
- Some good examples – Medway, York Railway Station

Project Lead, Dementia Friendly Hampshire - Debbie Morshead (Andover Mind)

- Dementia Friendly Hampshire Project commenced in March 2013 (Phase 1 was up to 2015)
- 1 full time and 6 part time employees – HCC funded
- 6 key objectives of the Dementia Friendly Hampshire Project:

- Consultation and engagement (C&E)
- Awareness
- Peer support – identify gaps in service provision
- Ambassadors – The face of the campaigns, championing the cause
- Hampshire Dementia Action Alliance (HDAA)
- Dementia Friendly High Streets
- Results achieved:
 - C & E - 141 events, 1025 people
 - Promotional Events – 249
 - Dementia Ambassadors – 26
 - Dementia Action Groups – 10 firm, 16 under development
 - Awareness - 348
 - Dementia Friends - 3404
 - Peer Support (new groups) - 23
 - HDAA - 440
 - Dementia Friendly High Streets - 10
- Dementia Friendly Hampshire look after the admin to enable the various Dementia Action Groups to focus on making a difference in the community and fund raising.
- Hampshire Constabulary and Fire and Rescue are signed up
- Good practice / How to guides have been developed for businesses and shopping centres.
- Top tips to creating dementia friendly communities:
 - Keep it personal
 - Be flexible
 - Sufficient resources and consider sustainability early in process
 - Communication is key
 - Let communities lead but key has been a dedicated team to oversee and kick start process
 - Involve everyone
 - Enjoy!
 - Southampton – Opportunities for inter-generational work with student population.

Commissioner, Southampton Integrated Commissioning Unit - Amanda Luker

- A Dementia Partnership exists in Southampton. Would like to establish a Dementia Action Alliance.
- Last year, working with a range of voluntary sector providers, a number of social activity groups were provided funding for 1 year to pilot initiatives. Including – art, seafaring, singing for the brain, walking, green care project at Down to Earth community farm.
- Some groups have been successful and have secured alternative funding. Some groups were not well attended and may not have been what people with dementia were looking for.
- Memory Cafes in the city supported by Admiral Nurses.
- Gaps in the city identified include – Awareness in care homes / residential homes, buses, engagement work about what people in Southampton want.

Conclusions from meeting:

- Significant benefits associated with communities becoming dementia friendly.
- Clear merits in having a dedicated team to oversee and kick start the process of becoming dementia friendly.
- Good practice exists in Hampshire and elsewhere and there are clear opportunities to learn from others.
- Need to ensure that people with dementia and their carers are fully engaged in the process.
- More Dementia Friends are needed.
- There is enthusiasm and support to make Southampton dementia friendly – start the process asap and don't wait until the inquiry is finished to make a difference.

Inquiry Meeting 2 – 29 October 2015

Challenge Stigma, Acknowledge Potential, Engagement in Community Life & Accessible Community Activities

- 6 Panel Members attended the Dementia Friends awareness session on 26th October 2015.

Summary of information provided:

A Public Health Perspective – Sue Dewhirst, Public Health Support Manager, Public Health England (PHE) & Sally Denley, Public Health Development Manager, SCC

- A briefing paper providing an update on current dementia projects undertaken by PHE and PHE South East (Wessex) was circulated. [Public Health England Briefing](#)
- Dementia is one of the 7 key priorities for PHE.
- Recognition that the uptake of Dementia Friends awareness sessions in Southampton needs to be increased. There is a need to identify gaps in the city where Dementia Friends sessions could be delivered.
- Opportunities to increase awareness across SCC by including Dementia Friends awareness session in the new employee induction programme and to make it compulsory for every customer facing employee and Councillor to attend a Dementia Friends awareness session.
- PHE are developing awareness and prevention leaflets and posters. There is value in ensuring these are distributed throughout the network of community centres and notice boards across Southampton, as well as through social media and the council's website.
- The Wessex Academic Health Science Network - Hoping to introduce John's campaign to UHS and Southern and Solent hospital services in Southampton; working well with GP Surgeries to make them dementia friendly; opportunity to develop a **dementia roadmap** for Southampton (a web based platform that provides information about the dementia journey alongside local information

about services, support groups and care pathways). More details from Katherine Barbour in December.

- Good practice regarding the NHS Health Checks (NHS HC) in Southampton - local training sessions last year to look at signs and symptoms of dementia and the role of the awareness raising in the NHS HC. This was run by Southern Health, Solent and Public Health (SCC) – 1 hour sessions in GP surgeries to capture the practice nurses and HCAs.
- Good feedback about it. During this training we decided to change our protocol around the awareness raising and ensure that all people seen for an NHS HC are told that the risk factors for Cardiovascular Disease are the same for Vascular dementia – promoting raising awareness from age 40+ rather than the recommended over 65s when it is potentially too late.

Lead Admiral Nurse, Solent NHS Trust – Karen Cotton

- Admiral Nurses are specialist dementia nurses who give practical and emotional support to family/informal carers, as well as the person with dementia.
- They have provided training sessions for Solent NHS employees on dementia awareness. This has helped Solent NHS employees to deliver dementia screening as part of their visits, helping to raise awareness and diagnosis of dementia in Southampton.
- Confidence is key to acknowledging potential and for people with dementia to engage in community life. Admiral Nurses work with people with dementia to give them confidence to understand and manage risk and to keep doing things they were doing pre-diagnosis as this is usually preferable to creating specialist activities.
- Society can be supported to become more confident in supporting people with dementia to enable them to continue to undertake social activities. Dementia Friends awareness is very important in building confidence within communities. More can be done in Southampton to encourage community groups, societies, cafes, churches and pubs etc to be dementia friendly.
- Specific issues raised related to the provision of respite care, and the importance of a range of respite options for carers to choose from, and the variation in the approach and attitude of banks towards people with dementia.

Services Manager South Hampshire, Alzheimer's Society - Gary Walker

- A presentation was delivered by Gary Walker - [Alzheimer's Society Presentation](#)
- Historically Alzheimer's Society have not been very active in Southampton. Following the recent grant award from the ICU activity levels are growing.
- Alzheimer's are working with Memory Advisors and Admiral Nurses. Working together we can make a difference to help people living with dementia (Inc. carers) stay in control for longer.
- Alzheimer's now run a number of groups in Southampton although sustainability is a concern. Potential to significantly increase reach to people and their carers who live with Dementia in Southampton.

- Working in partnership with Southampton Football Club has opened up opportunities to increase the number and sustainability of groups, with the potential to bring in additional external funding.
- 'One Million Hands' Partnership with the Scouts could help to reduce the stigma by 'normalising' dementia amongst this generation. Targeting schools is key.
- It is important that there is an increase in the numbers of Dementia Friends within Southampton; stronger links are developed with Mental Health; referral routes into social activities are improved; operational support is provided for a local structure in Southampton to develop and maintain a sustainable DFC (see recommendation from report on Consultation feedback).

Arts Council

- Amanda Luker, Commissioner within the ICU, outlined the funding opportunities that are available from the Arts Council to help support people with dementia.

Conclusions from meeting:

- Dementia Friends can make a significant difference to reducing stigma, and increasing engagement in community life. More Dementia Friends are needed in Southampton.
- Opportunities exist to increase awareness in the council by making Dementia Friends sessions compulsory for all customer facing employees and including it in council inductions.
- Activity and awareness is growing in Southampton. Co-operation and co-ordination is essential to maximise opportunities and effectiveness to support people with dementia and their carers. A Dementia Action Alliance would help this process.
- Need to improve referral routes into social activities.
- Explore funding opportunities from the Arts Council.

Inquiry Meeting 3 – 19 November 2015

Community Based Solutions

Summary of information provided:

Lecturer in Gerontology: Centre for Research on Ageing, University of Southampton - Dr Rosalind Willis

- A presentation was delivered by Dr Willis - [Insights from a Gerontologist's research](#)
- The numbers of people with dementia are not increasing as quickly as was once predicted - Potentially due to healthier lifestyles, better education, improvements in care, etc.
- Carers who had familiarity with the social care system were more satisfied

- Many South Asian carers viewed social services as fulfilling an important role, and something to be used when absolutely necessary (at crisis point) - Formal social services are not incompatible with British Asian cultural values
- 'One-stop-shop' memory clinics can provide access to a range of helpful services (joined-up care)
- Continuity of care is valued and important in dementia care
- Need to improve communication between social services and carers/service users at every stage of the process: Outreach, assessment, meet language needs at all stages, more follow-up calls / visits (not dropped from caseload)
- These issues are particularly problematic for the South Asian group, who had additional barriers to knowledge about social care services.

Associate Director of Quality, Integrated Commissioning Unit – Carol Alstrom

- Mixed picture regarding care homes in Southampton and supporting people with dementia. Some homes are responding to the dementia challenge (Fair Havens care home is exceptional and has even trained kitchen staff as well as care staff). The ICUs role is to drive up standards amongst the 9 nursing homes and 54 residential care homes.
- Care homes can take an assessment against a 'dementia friendly' toolkit. The ICU is encouraging this and is supporting care homes to make improvements.
- A number of training sessions focussing on dementia awareness and support for People with dementia (PWD) are offered by SCC.
- Dignity Champions Network & Dignity Forum; Residential Homes Forum; Bi-monthly meeting of Registered Managers all help to raise the profile of dementia awareness and share good practice across care homes in Southampton.
- The creation of the ICU has helped with co-ordination and communication. Providing staff training on dementia is a contracting criteria for care homes that provide services for PWD.
- Good progress made but need to build on work developed through the Domiciliary Care Framework and transfer this to care homes.
- Training is an ongoing challenge because of high staff turnover in sector (as much as 50%). Estimated that around 25% of employees have been provided with dementia awareness sessions.

Integrated Care Transformation Manager, Integrated Commissioning Unit - Moraig Forrest-Charde

- A presentation was delivered by Moraig Forrest-Charde – Southampton Better Care vision
- The Southampton Better Care Plan should contribute to improving the lives of PWD by ensuring that care is integrated and centred on the needs of the individual, and that services are more proactive at identifying need.
- The new Domiciliary Care Framework commenced in spring 2015. 14 agencies are now delivering care to 1,200 people in their own homes (if council funded). This is a significant reduction in agencies.
- The new framework has a strong emphasis on staff awareness and skills

- The new framework has resulted in a number of improvements through improved communications and trust, sharing good practice and improving quality through stronger relationships.
- Working with agencies to provide personalised services – Working towards flexible care and support plans (inc banking time when the individual needs more care).
- Providers undergo ICU led quality reviews that supports the performance and contract meetings.
- The Domiciliary Care Forum meets quarterly – Working to improve outcomes and make framework a success.
- Good engagement with GPs, working closely with SCC Housing Services and now beginning to reach out to housing associations. Looking for council support to access private landlords.

Head of Housing Services, SCC – Nick Cross & Supported Services Manager, SCC – Jean Brown

- A presentation was prepared by Nick Cross and Jean Brown – [Housing Services](#)
- SCC Housing Services deliver a number of supported housing schemes across the city to help people to live independently.
- SCC has invested in buildings to improve standards. New builds include Erskine Ct an Extra Care development built following HAPPI principles (Housing our Ageing Population Panel for Innovation) with a development planned at Woodside Lodge.
- New build schemes are easier than re-designing existing properties such as Graylings and Manston Ct, a vibrant scheme that has been re-modelled using designing for dementia principles.
- Specific housing initiatives are supported by the ‘Decent Neighbourhoods Programme’ that has been improving the public realm and communal spaces using design guidelines, and the programme of adaptations to homes to enable people to continue to live independently.
- Dementia Friendly Fun Fridays – Successful volunteer led initiative from Marston Ct. Preliminary findings show that for every £1 invested there has been a £44.69 return in wellbeing and social value.
- Working with the Saints Foundation.
- All housing staff working with older people have undertaken dementia awareness sessions. In Supported Services 3 or 4 officers are Dementia Champions.
- Number of opportunities and challenges for housing including transport; engaging local businesses and communities with housing schemes (Graylings off Shirley High example of scheme struggling to engage with community); supporting younger people with dementia and ensuring that the right tenants are in the properties; and exploring the potential of telecare in the city (including working with partners such as Hampshire Constabulary).
- Telecare – Potential to further engage with Hampshire Constabulary to link with developing technologies to help locate people with dementia that go missing.

Conclusions from meeting:

- Evidence of strong links and integrated services between housing / Integrated Commissioning Unit / domiciliary care / residential and nursing care that are helping to provide community based solutions for people with dementia.
- Recognition of importance of training and dementia awareness – Consider dementia awareness training for Action Line staff.
- As part of the development of telecare in the city SCC could further explore the potential of engaging with Hampshire Constabulary to utilise new systems to locate people with dementia that have gone missing.

Inquiry Meeting 4 – 3 December 2015

Respectful and Responsive Business and Services
Consistent and Reliable Travel Options

Summary of information provided:**Health & Wellbeing Development Officer, Age UK Southampton – Phil Williams**

- Age UK Southampton are working closely with Business in the Community (BITC) to encourage businesses to support local voluntary organisations. Working with their Community Social Responsibility reps is often productive. It is a win/win situation for businesses and communities.
- Key to dementia friendly high streets is to work with a community that is enthusiastic and start small, if it is seen to work it will escalate.
- Need to engage with banks and post offices.
- Dementia Friends awareness is key. Get staff in businesses aware of dementia.
- Age UK Southampton are leading a review into assisted transport for older people. Engaging with SCA and SCC.
- Age UK Southampton have undertaken an office environment audit to become a dementia friendly office through a national Age UK initiative working with Innovations in Dementia. It was a simple process that identified the importance of clear signage so that people with dementia know that they are in the right place, where the toilets are and how to navigate themselves back to where they need to be.

Senior Programme Manager, Wessex Academic Health Science Network (WAHSN) & Dementia Friendly Portswood High Street Volunteer – Katherine Barbour

- [Handout](#) provided on the work of the WAHSN focussing on dementia.
- ISPACE programme to make GP surgeries dementia friendly – The Old Fire Station Surgery was the first to complete the process and others are in train but only 10% of Southampton GP practices have engaged in the initiative so far.
- Acute Development Programme – UHS has an active Memory Café, Admiral Nurses are engaged, Memory Box (Wessex Heritage Trust Lottery Funded

initiative) on wards at UHS and all Wessex acute hospitals are either signed up to, or in the process of signing up to John's Campaign (campaign that carers of people with dementia should have the same rights as the parents of children when admitted to hospital).

- Portswood, Highfield and St Denys Dementia Action Group are attempting to make Portswood a Dementia Friendly High Street – Active steering group meets regularly.
- Progress has stalled – Hampshire had paid employees driving progress. It is a big time commitment for volunteers. Would like to work with Dementia Champions.
- Continuing to deliver Dementia Friends information sessions on a monthly basis.
- Would support a 'DemFest' in Southampton in 2016.

Travel and Transport Manager, Southampton City Council – Paul Walker

- A [presentation](#) was delivered by Paul Walker on legible cities and networks and the improvements made to the branding, consistency and legibility of signage in Southampton.
- Improved stop kerb facilities to make getting on and off buses easier, and through the Better Bus area funding installed next stop audio and visual announcements on buses across South Hampshire.
- Many services are route branded to assist people getting on the right bus.
- Developing "super stops" which are easier to use.
- Recognition that the council could use its influence to ensure that new travel and transport schemes in the city incorporate dementia friendly design principles, especially when the council part funds initiatives.
- The Travel and Transport Manager would review the Key Performance Indicators used to monitor the contract with SCA to see if they identified support for people with dementia.

General Manager, Bluestar, Southern Vectis & Unilink at Go South Coast Ltd – Matt Kitchin

- A presentation was prepared by Matt Kitchin – [Go South Coast](#)
- Recently launched new fleet of buses with light coloured flooring designed following feedback from people with dementia.
- Engaged in the Dementia Alliance on the IOW – used a bus to raise awareness of dementia on the Island that is utilised by the NHS. The initiatives brought people with dementia back onto the IOW bus network.
- Extensive dementia awareness initiatives undertaken by staff, including all drivers, and it is now embedded into the Certificate of Competency Training Course (CPC).
- Rolling out safe journey cards across the network. Options to include a phone number of a contact on the card.
- Communicate timetable changes on set times each year. Alongside publication of new route specific timetables they work with the Daily Echo, Pensioners Forum and hospital groups to raise awareness of any timetable

changes. Timetables are distributed wherever they are requested including libraries. Inevitable not all people are informed.

- Willing to work with Age UK to designate the Bluestar office in Southampton a 'Safe Haven'.

Business Performance Director, First Hampshire, Dorset & Berkshire. General Manager, Southampton - Chrissie Bainbridge

- A presentation was prepared by Chrissie Bainbridge – [First Bus](#)
- Driver training on dementia awareness – A CPC module is undertaken by drivers developed in conjunction with Alzheimer's Society and the Mental Health Action Group.
- Heart-warming to see the change in attitude of some drivers following the sessions. Training has been hugely beneficial and feedback has been positive.
- Need to do more to roll out awareness sessions across all staff groups.
- Safe Journey cards issued similar to Go South Coast Ltd and next stop audio on buses is working. Radios on board buses have also been used to look out for people with dementia that have gone missing.
- Timetables are provided in one book, not route specific timetables. Sent to anybody who asks for it or is on the mailing list.
- Happy to work with Age UK for First offices to become a 'Safe Haven'.

Conclusions from meeting:

- Consider office environment audit for all SCC customer facing buildings.
- Potential for DemFest 2016 in Southampton.
- Opportunity for the council to use its influence to ensure that new travel and transport schemes in the city incorporate dementia friendly design principles, especially when the council part funds initiatives.
- Progress is being made by SCC and bus operators to make services more dementia friendly.

Inquiry Meeting 5 – 21 January 2016

Ensure an early diagnosis

Summary of information provided:

Clinical Programme Lead for Mental Health NHS Southampton City Clinical Commissioning Group - Dr Cliff Howells

- 70% diagnosis rate for dementia in Southampton. Diagnosis rates have increased dramatically due to work across the system.
- GP's are getting better at diagnosing dementia. Tests for dementia will improve.

- The City Council's website is a useful tool for signposting people to support. Financially it is better to have these tools signposting people with dementia (PWD) and their carers to support rather than GP's themselves.
- In the city Community Navigator roles are available to individuals living with dementia and their carers to provide a way of linking people up to activities and services in the community that they may benefit from, including non-medical services providing social, practical or emotional support.
- Within Primary Care support for PWD includes a wider team of professionals than just GP's. Senior Nurse Practitioners are increasingly being used to support and diagnose PWD.
- The Better Care Fund is leading to closer integration between health and social care. Systems on the ground are being streamlined leading to better outcomes for PWD. There is more to do.
- Encouraging Southampton GP Practices to sign up to ISPACE (programme to make GP surgeries dementia friendly) – Once a few surgeries start to demonstrate the benefits of ISPACE this initiative will roll out quickly across the city.
- BME communities – Cultural issues can deter people from BME communities in Southampton from accessing services at the right time, or at all. Accessing the community is key. Identified good practice includes outreach through the mosques and temples and into West Itchen Trust.
- There is an issue of ensuring that dementia awareness and support leaflets are available in GP Surgeries.

Consultant Psychiatrist, Older People Mental Health, Southern Health NHS Foundation Trust - Dr Maged Swelam

- Memory Clinics are run by Southern Health at Moorgreen Hospital and Western Community Hospital. Assessments are also undertaken in the community.
- Early referrals from primary care has increased. 47% of primary care dementia referrals to Southern Health are for people with mild cognitive impairments. In 2008 not many patients were seen at this early stage.
- Secondary care memory assessment are not self-referral, however the memory advisory service will accept referrals from a number of sources including self-referral.. All contact is followed up by a letter to their GP.
- Southern Health will continue to see people in clinics until they are stable. Memory Advisors signpost people to services.
- Services are now working more collaboratively. In the last 18 months following the establishment of the Better Care Fund there is improved working across sectors (primary care, acute, mental and physical health, and adult social care). Dr Swalem meets on a regular basis with stakeholders from across the system, including the Admiral Nurses, GP's and housing services, to address issues and improve outcomes for patients. Organisational boundaries are becoming blurred.
- Memory checks are now part of the NHS Health check programme.
- In Southampton Southern Health and GP's encourage PWD to talk about financial issues, including power of attorney, at an early stage.

- Loneliness is an issue across the city. It has been linked in some studies to an increased risk of Alzheimer's disease. There is a need to signpost these people to activities in voluntary groups.

Conclusions from meeting:

- Diagnosis rates in Southampton have significantly improved.
- The closer integration of health and care services is helping streamline processes. There is increasing collaboration and sharing good practice.
- More work is required through the Better Care Fund to improve the service received by PWD and their carers.
- There is an issue of ensuring that dementia awareness and support leaflets are available in GP Surgeries.
- Combating loneliness would help to address a number of issues in the city.
- The LGA has recently published a guide to [combating loneliness](#) for local authorities.

Inquiry Meeting 6 – 25 February 2016

Easy to navigate environments

Summary of information provided:

Associate Professor in Ageing and Social Research, Faculty of Health Sciences, University of Southampton - Dr Ruth Bartlett

- A [presentation](#) was delivered by Dr Bartlett.
- In addition to the understood memory problems dementia also impacts on sensory abilities. Therefore design is important for people with dementia (PWD).
- PWD cannot always process what they see properly. It effects vision and hearing so flooring and music in retail centres can be problematic.
- PWD have rights to expect effective measures to be taken to promote social inclusion and mobility under the UN Convention on the Rights of Person with a Disability.
- Six design principles for a Dementia Friendly Community
 1. Familiarity
 2. Legibility – Southampton's is generally clear and good
 3. Distinctiveness
 4. Accessibility
 5. Safety
 6. Comfort
- New technologies are being developed to support PWD (linked to discussion on telecare and housing at meeting 3).

City Design Group Leader, Southampton City Council – Darren Shorter

- In November 2015 SCC published a [Streets and Spaces Framework](#) that sets out public realm design guidance for Southampton city centre that expresses, in greater detail, the aspirations set out in the City Centre Action Plan.
- The 6 principles of design for PWD are the same principles for good place making within the public realm.
- In developing the Framework a number of studies of design environments with health issues in mind were reviewed.
- The Framework recognises that the physical environment impacts on people's mental health and encouraging better connected environments.
- Key design themes, following stakeholder engagement, include:
 1. Continuity and consistency in design
 2. Legibility
 3. Comfort – Massive increase in seating in city centre over past decade
- Looking at opportunities to connect the new and emerging landmarks in the city together, and to reclaim some streets that are not main transport thoroughfares for pedestrians.
- Consideration to be given to removing curbing on pedestrian streets.
- General consensus that signage in the city is clear and increasingly consistent.
- Effective maintenance of the public realm is important. Maintenance costs are factored into the planning and design of the public realm in Southampton.
- The next Local Plan is in development. Opportunities to consult PWD in the development of the Local Plan.
- Opportunity for University of Southampton 'dementia experts' to give feedback on the Streets and Spaces framework to ensure it reflects the specific needs of PWD.
- Concerns were expressed about the availability of public toilet facilities in the city. A number of cities have a community toilet scheme that enables local businesses like pubs, restaurants and shops, to work together with the Council to make additional clean, safe and accessible toilets available to the public.

Community Manager, Hammerson – Jonathan Brookes

- A [presentation](#) was delivered by Jonathan Brookes
- Hammerson (owners of West Quay, as well as the emerging Watermark West Quay) recognises that there exists ethical and commercial drivers to making the retail experience dementia friendly.
- Hammerson have developed a Dementia Friendly Charter for all of their shopping centres. A toolkit runs alongside this. This reflects the BSCS Dementia Friendly Guide 2015.
- The Charter identifies 4 key areas that Hammerson retail centres will focus on: Improving staff awareness and understanding; Reviewing our store's physical environment; Supporting our employees affected by dementia; Support our local community to become more dementia friendly.
- A number of developments have taken place in West Quay to make the design of the centre more Dementia Friendly. This includes improving the acoustics to reduce background noise; installing comfortable seating;

improving lighting levels at entrances and exits; improving wayfinding to toilets and accessible disabled facilities.

- Further adaptations to the physical environment are planned at West Quay including: An audit by third party to support creation of revised action plan; Providing a quiet space in stores for people to sit and relax; Project to improve overall way finding- this will assist a person who may have dementia to find entrances, exits and toilets; Car parks - Marked bays with colour coding scheme and improved pedestrian access routes; Retailer Engagement - Tenant fit out manual guidelines and retail delivery guide.
- People focussed changes planned include: Training and awareness - Dementia champions and training for all front line staff; Dementia-friendly customer service - focus on increasing staff awareness; Retailer Engagement - monthly meetings, retail liaison and mystery shopping.
- Supporting the local community – A community plan exists for West Quay, working with local stakeholders; Encourage the use the centre as a community space for initiatives such as Dementia Friends session and ‘tea and talk; Keen to engage in Dementia Awareness Week; Seed funding exists to set projects up, this could help support Dementia Friendly Community initiatives in Southampton.
- Dementia awareness training – Very early stages regarding working with retailers but rolling this out for Hammerson employees.

Conclusions from meeting:

- Due to sensory and cognitive challenges design is important to enable PWD to continue to be active citizens.
- New technologies are being developed to support PWD
- The Council’s new Street and Spaces Framework incorporates the principles of design for PWD within the principles for good place making within the public realm.
- Opportunities exist to consult PWD in the development of the Local Plan.
- Opportunity for University of Southampton ‘dementia experts’ to give feedback on the Streets and Spaces framework to ensure it reflects the specific needs of PWD.
- Consideration should be given to implementing a community toilet scheme in Southampton.
- Positive developments at West Quay for PWD. Opportunities exist to work with Hammerson to support local dementia awareness initiatives and to engage with the Council & CCG on events marking Dementia Awareness Week, including the New Arts Centre.

Appendix 4 – Findings

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
<p>General Co-ordination and Strategic Direction</p>	<ul style="list-style-type: none"> • Hampshire Constabulary and Hampshire Fire and Rescue are already signed up to Hampshire’s Dementia Action Alliance. • Good neighbour scheme being explored/developed. 	<ul style="list-style-type: none"> • Co-operation and co-ordination is essential to maximise opportunities and effectiveness to support people with dementia and their carers. • Opportunity exists for the Council to use its influence to promote the needs of people living with dementia. • Loneliness is an issue across the city. It has been linked in some studies to an increased risk of Alzheimer’s disease. Combating loneliness would help to address a number of issues experienced in the city, including progressing dementia friendly Southampton. 	<ol style="list-style-type: none"> 1. That the Integrated Commissioning Unit engages an organisation to oversee and kickstart the drive to becoming dementia friendly. 2. That the successful applicant /organisation submits an application to the ‘working to become dementia friendly’ on behalf of Southampton. 3. That the Council works with existing members of the Southampton Dementia Partnership to establish a Dementia Action Alliance in Southampton. 4. That the Council use strategic drivers such as the community safety plan, health and wellbeing strategy, local transport plan, planning function as well as strategies for older people and people with dementia as levers to reinforce the needs of people living with dementia. 5. That the Council seeks to deliver the recommendations locally identified within the Local Government Associations recently published guide to combating loneliness.

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
<p>Challenge stigma and build understanding</p>	<ul style="list-style-type: none"> • Activity and awareness is growing in Southampton. • ‘One Million Hands’ Partnership with the Scouts could help to reduce the stigma by ‘normalising’ dementia amongst this generation. 	<ul style="list-style-type: none"> • More Dementia Friends are needed in Southampton. • Opportunities exist to increase awareness in the Council. • Demfest 2015, that took place at the Sir Harold Hillier Gardens, raised awareness of dementia across Hampshire. 	<ol style="list-style-type: none"> 6. That Dementia Friends sessions are made compulsory for all customer facing Council employees, including Councillors, and that it is included in Council / Capita inductions. 7. That the Council supports key staff and elected members to become dementia champions – so they can train and support other members and officers to become dementia friends and to act as ambassadors and supporters of work to promote dementia friendly communities locally. 8. In partnership with the recommended Southampton Dementia Action Alliance a ‘Southampton DEMFEST’ is organised in 2017.
<p>Accessible community activities</p> <p>Acknowledge potential</p>	<ul style="list-style-type: none"> • Working with a range of voluntary sector providers, a number of social activity groups were provided funding for 1 year to pilot initiatives. Including – art, seafaring, singing for the brain, walking, green care project at Down to Earth community farm. • Mapping socials networks and existing resources, ensuring that these are 	<ul style="list-style-type: none"> • Supporting organisations to secure external funding from businesses to secure long term future by developing sustainable economic model. • Potential to significantly increase reach to people and their carers who live with Dementia in Southampton. 	<ol style="list-style-type: none"> 9. With the opening of the new arts centre imminent explore funding opportunities from the Arts Council to facilitate accessible activities for people with dementia. 10. Explore the opportunity to create a dementia roadmap for Southampton.

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
Practical support to enable engagement in community life	<p>recorded and updated on a single portal; Southampton Information Directory</p> <ul style="list-style-type: none"> Admiral Nurses, specialist dementia nurses who give practical and emotional support to family/informal carers, as well as the person with dementia are active in Southampton. Memory Cafes, Memory Advisers 	<ul style="list-style-type: none"> Need to improve referral routes into social activities. Opportunity to develop a dementia roadmap for Southampton (a web based platform that provides information about the dementia journey alongside local information about services, support groups and care pathways). 	
Community-based solutions	<ul style="list-style-type: none"> SCC Housing Services deliver a number of supported housing schemes across the city to help people to live independently. SCC has invested in buildings to improve standards. New builds include Erskine Ct an Extra Care development built following HAPPI principles (Housing our Ageing Population Panel for Innovation) with a development planned at Woodside Lodge. New build schemes have been re-modelled using designing for dementia principles. Dementia Friendly Fun Fridays – Successful volunteer led initiative from Marston Ct. Preliminary findings 	<ul style="list-style-type: none"> New technologies are being developed to support people with dementia. Potential to further engage with Hampshire Constabulary to link with developing technologies to help locate people with dementia that go missing. 	<p>11. That the City Council’s Housing Services engages with Hampshire Constabulary to utilise new systems to locate people with dementia that have gone missing.</p>

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
	<p>show that for every £1 invested there has been a £44.69 return in wellbeing and social value.</p> <ul style="list-style-type: none"> • All housing staff working with older people have undertaken dementia awareness sessions. In Supported Services 3 or 4 officers are Dementia Champions. • Evidence of strong links and integrated services between housing / Integrated Commissioning Unit / domiciliary care / residential and nursing care that are helping to provide community based solutions for people with dementia. • The creation of the Integrated Commissioning Unit has helped with co-ordination and communication. 		
Ensure an early diagnosis	<ul style="list-style-type: none"> • 70% diagnosis rate for dementia in Southampton. Diagnosis rates have increased dramatically due to work across the system. • GP's are getting better at diagnosing dementia. Tests for dementia will improve. • Early referrals from primary care has increased. 47% of primary care dementia referrals to Southern Health 		

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
	<p>are for people with mild cognitive impairments. In 2008 not many patients were seen at this early stage.</p> <ul style="list-style-type: none"> • Services are now working more collaboratively. The Better Care Fund is leading to closer integration between health and social care. Systems on the ground are being streamlined leading to better outcomes for people with dementia. • Memory checks are now part of the NHS Health check programme. 		
<p>Respectful and responsive businesses and services</p>	<ul style="list-style-type: none"> • ISPACE programme to make GP surgeries dementia friendly. The Old Fire Station Surgery was the first to complete the process and others are in train. • Portswood, Highfield and St Denys Dementia Action Group are attempting to make Portswood a Dementia Friendly High Street – Active steering group meets regularly. • Age UK Southampton are working closely with Business in the Community (BITC) to encourage businesses to support local voluntary organisations. 	<ul style="list-style-type: none"> • Only 10% of Southampton GP practices have engaged in the ISPACE initiative so far. • Progress has stalled at Portswood, Highfield and St Denys Dementia Action Group – Hampshire has paid employees driving progress. 	<p>12. Through the Health and Wellbeing Board and NHS Southampton CCG General Assembly Southampton GP Practices are actively encouraged to sign up to the ISPACE initiative.</p>

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
<p>Consistent and reliable travel options</p>	<ul style="list-style-type: none"> • Improved stop kerb facilities to make getting on and off buses easier, and through the Better Bus area funding installed next stop audio and visual announcements on buses across South Hampshire. • Progress is being made by SCC and bus operators to make services more dementia friendly. • Bluestar recently launched a new fleet of buses with light coloured flooring designed following feedback from people with dementia. • Rolling out safe journey cards across the network • Extensive dementia awareness initiatives undertaken by bus operators, including all drivers, and it is now embedded into the Certificate of Competency Training Course. 	<ul style="list-style-type: none"> • Opportunity for the council to use its influence to ensure that new travel and transport schemes in the city incorporate dementia friendly design principles, especially when the council part funds initiatives. • Transport issues identified as a major issue by Cluster Community Action Group workshops, the ICU are mapping need and co-designing a solution. 	<p>13. That the Council ensures that new travel and transport schemes in the city incorporate dementia friendly design principles.</p>
<p>Easy-to-navigate environments</p>	<ul style="list-style-type: none"> • SCC published a Streets and Spaces Framework that sets out public realm design guidance for Southampton city centre that expresses, in greater detail, the aspirations set out in the City Centre Action Plan. The 6 	<ul style="list-style-type: none"> • The next Local Plan is in development. Opportunities to consult people with dementia in the development of the Local Plan. • Opportunity for University of Southampton 'dementia experts' to 	<p>14. That City Council Planning Officers consult groups representing people with dementia in the development of the Local Plan.</p> <p>15. That dementia experts at the University of Southampton are</p>

Key Area of Focus for communities working to become dementia friendly	Positive Developments in Southampton	Weaknesses / Opportunities for Southampton	Recommendations
	<p>principles of design for people with dementia are the same principles for good place making within the public realm.</p> <ul style="list-style-type: none"> • Improvements made to the branding and legibility of signage in Southampton. General consensus that signage in the city is clear and increasingly consistent. • Positive developments at West Quay for people with dementia. • Age UK Southampton have undertaken an office environment audit to become a dementia friendly office through a national Age UK initiative working with Innovations in Dementia. 	<p>give feedback on the Streets and Spaces framework to ensure it reflects the specific needs of people with dementia.</p> <ul style="list-style-type: none"> • Opportunities exist to work with Hammerson to support local dementia awareness initiatives and to engage with the Council & CCG on events marking Dementia Awareness Week, including the New Arts Centre. • Opportunity for an office environment audit for all SCC customer facing buildings. • Concerns were expressed about the availability of public toilet facilities in the city. A number of cities have a community toilet scheme that enables local businesses like pubs, restaurants and shops, to work together with the Council to make additional clean, safe and accessible toilets available to the public. 	<p>invited to give feedback on the Streets and Spaces framework to ensure it reflects the specific needs of people with dementia.</p> <ol style="list-style-type: none"> 16. The Council/CCG proactively engages with Hammerson to identify how their resources, enthusiasm and expertise can be utilised to increase support for dementia friendly Southampton. 17. That office environment audits are undertaken on all City Council customer facing buildings. 18. That the City Council explores opportunities to develop a Community Toilet Scheme in Southampton.

Appendix 5

Types of Dementia - The dementia guide published by the Alzheimer's Society.

Alzheimer's disease

Inside the brain

Abnormal material called 'plaques' and 'tangles' builds up in the brain. This disrupts how nerve cells work and communicate with each other, and the affected nerve cells eventually die.

There is also a shortage of some important chemicals in the brain when someone has Alzheimer's disease. Reduced levels of these chemicals mean messages don't travel around the brain as well as they should.

Early symptoms

Alzheimer's disease usually begins gradually with mild memory loss. This is because the first changes in the brain are often in the part that controls memory and learning. A person with Alzheimer's disease might forget people's names or where they have put things. They might also have problems with language, such as finding the right word for something.

Other early symptoms include feeling confused or finding it hard to follow what is being said. Some everyday activities might seem challenging, for example, someone might get muddled checking change at the shops. Some people also become more withdrawn and experience mood swings.

Vascular dementia

Inside the brain

The word 'vascular' relates to blood vessels. Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain (called subcortical vascular dementia).

Strokes happen when a blood clot blocks the flow of blood to part of the brain, or when a blood vessel bursts in the brain. Vascular dementia sometimes follows a large stroke. More often though, it comes after a number of small strokes (called multi-infarct dementia).

Subcortical vascular dementia – when there is poor blood flow to the deep parts of the brain – is often due to narrowing of the arteries supplying the brain.

Early symptoms

If someone has had a large stroke, symptoms of vascular dementia can begin suddenly. Symptoms can then remain stable or even get a little bit better over time in the early stages. If the person has another stroke, these symptoms might get worse again.

If someone has a series of small strokes, their symptoms may remain stable for a while and then get worse in stages (rather than have a gradual decline). With subcortical vascular dementia, symptoms may get worse gradually or in stages.

The symptoms of vascular dementia will depend on which part of the brain has been damaged. Some people might have physical weakness on one side due to a stroke. Other changes include difficulty thinking quickly or concentrating and there might be short periods when they get very confused. Some people might also become depressed or anxious. Memory loss isn't always a common early symptom.

Mixed dementia

It's possible for someone to have more than one form of dementia – called mixed dementia. The most common combination is Alzheimer's disease with vascular dementia. It's also possible to have a combination of Alzheimer's disease and dementia with Lewy bodies.

Dementia with Lewy bodies

Inside the brain

This form of dementia gets its name from tiny abnormal structures called Lewy bodies that develop inside brain cells. Similar to the plaques and tangles of Alzheimer's disease, these structures disrupt the way the brain functions, reducing levels of chemical messengers and causing cells to die.

Lewy bodies are also found in people with Parkinson's disease. One third of people who have Parkinson's disease eventually develop dementia (called Parkinson's disease dementia).

Early symptoms

People who have dementia with Lewy bodies might find it hard to remain alert and have difficulties planning ahead, reasoning and solving problems. These symptoms typically vary a lot from one day to the next.

People might have problems with how they see things. For example, it might be hard to judge distances or they might mistake one object for another. Many people see things that aren't really there (visual hallucinations). Disturbed sleep patterns are also common.

However, if someone has dementia with Lewy bodies, their memory will often be affected less than someone with Alzheimer's disease. Many people with dementia with Lewy bodies also develop symptoms like those in Parkinson's disease, including shaking (especially in the hands), stiffness and difficulty moving around.

Frontotemporal dementia

Inside the brain

The term frontotemporal dementia covers a range of conditions. It was originally called Pick's disease and this term is sometimes still used. Frontotemporal dementia mostly affects people in their 40s, 50s and 60s (younger than most people who get Alzheimer's disease or vascular dementia). It's caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills.

In most cases, abnormal proteins collect within brain cells in these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

Early symptoms

There are three different forms of frontotemporal dementia – behavioural variant, semantic dementia and progressive non-fluent aphasia. With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. The person might seem withdrawn or not to care as much about other people. They might make socially inappropriate remarks. They may also become obsessive or impulsive, for example developing fads for unusual foods.

When someone has semantic dementia their speech is usually fluent but they lose the meaning or understanding of some words. Language is also affected in progressive non-fluent aphasia. Speech is often slow and requires a lot of effort.

People in the early stages of frontotemporal dementia often don't experience day-to-day memory loss.

Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are rare, and together account for only about 5% of all people with dementia. However, they are more common in younger people with dementia.

These diseases include:

- Corticobasal degeneration.
- Creutzfeldt-Jakob disease.
- HIV-related cognitive impairment.
- Huntington's disease.
- Alcohol-related brain damage and Korsakoff's syndrome.
- Multiple sclerosis.
- Niemann-Pick disease type C.
- Normal pressure hydrocephalus.
- Progressive supranuclear palsy.