



# Living Well with Dementia: A Strategy for Sefton 2014-2019

## Consultation Report

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# Summary Report

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This report provides a summary of the findings from the consultation and engagement process undertaken on Living Well With Dementia: A Strategy for Sefton 2014-19. The consultation and engagement process took place over during the summer of 2014 and included:-

- Two Open Space and Innovation Events held in Southport (1<sup>st</sup> July 2014) and Bootle (3<sup>rd</sup> July 2014) for providers of services, voluntary community faith sector, shops, businesses and offices
- A questionnaire specifically for people with dementia
- A questionnaire for carers of people with dementia
- A questionnaire for people who have recently lost somebody with dementia
- A general questionnaire for members of the public
- An easy read version of the general questionnaire which was used to engage with people with learning disabilities

In total, 169 people engaged with the process. These are some of the common themes that people raised as part of the consultation process:-

## Key findings from the Open Space and Innovation Events

### Creating Dementia Friendly Communities

- Communities need to understand dementia and offer support and challenge stigma
- Education is important
- Help people to make changes to live well with dementia and as normal as possible for as long as possible.

- Support carers so that they don't lose their own identity.
- Ask people with dementia what they want
- Process for businesses becoming “dementia friendly” is too complicated and onerous and needs to be simplified
- Early diagnosis is essential
- Care homes should become community hubs and have more interaction with the public

### Promoting diagnosis and supporting people to live independently

- Downes Syndrome: early screening for dementia for children/adults with Down's Syndrome as dementia statistically more prevalent in people with Down's Syndrome.
- There needs to be community based health services to maintain people in their homes for as long as possible
- There needs to be meaningful day services for people with dementia. People with dementia need activities that stimulate them.
- There needs to be a whole person approach – services need to be flexible to meet the needs of individuals.
- Need to promote the importance of getting early diagnosis. There are drug treatment and services available and early diagnosis needs to be viewed as positive.
- There needs to be easy access to Information, advice and guidance following diagnosis.
- There needs to be a structured pathway following diagnosis with other agencies involved in agreeing, developing and supporting it – information, advice, guidance, face to face, advocacy, networks and groups etc.

## Information, advice, support for people with dementia

- Carers struggle on without support because they don't know what is available or they don't want people to know they aren't coping.
- Family members don't know what signs to look for when somebody is struggling.
- People need to know where to go for advice and support - Dementia agencies, pharmacists, Age UK, SAGA, etc
- More needs to be done when people are diagnosed. People are diagnosed and then just left to get on with it with no information about where to go for support.
- Need to give positive messages about dementia. It's not all over just because you have dementia – it's not all doom & gloom. Use people who are living well with dementia as champions to promote positive messages.
- Information needs to be available using language that everybody can understand. Avoid using jargon and medical terms that people can't understand.

## **Key findings from questionnaire for People with Dementia**

- 7 people completed the questionnaire. This was facilitated by the Alzheimer's Society.
- On the whole people with dementia found it easy to get a diagnosis and that they had received enough information about their condition.
- Most people said that their GP noticed or that they noticed themselves that they were having problems.
- With regard to things that are working well for people with dementia one person felt that the time between being diagnosed and attending the memory clinic was too long, and another had found it difficult to adjust. Other respondents felt that the Alzheimer's Society was particularly helpful.

- One person had spent time in hospital and their experience was not good, with food being put out of reach, and not answering the bell during the night when they needed to use the commode.
- People that wanted to attend events and classes already do.
- Everybody that completed the questionnaire felt that everything that was important to them was covered.

## Key Findings from Questionnaires for Carers of People with Dementia

- 20 people completed the questionnaire and this was facilitated by the Alzheimer's Society and the Carers Centre.
- On the whole carers noticed themselves that the person they care for were having problems with their memory. The majority felt that it was very easy to get a diagnosis for the person that they care for and that professionals listened. 80% also said that they had received enough information about dementia.
- With regard to specific information that carers would have liked to have received this included more information about the long-term symptoms; how to go about choosing residential care and the costs involved and more information about aftercare following diagnosis.
- When asked what had gone well in their role as a carer of a person with dementia, comments related to
  - ❖ problems getting reliable carers
  - ❖ having to making all decisions by themselves
  - ❖ Lack of help with transport.
  - ❖ Working through the minefield of financial support

- When asked about what was important to them as a carer of a person with dementia, carers felt that in terms of healthcare for the person they cared for it was important that they saw the same person so that they didn't have to repeat their story and over again to different people.
- With regard to the person with dementia being asked what they want, including their likes and dislikes, even if they find it difficult to answer, most felt this was important.
- All those who completed the questionnaire felt that it was important that the person with dementia should have a say in their end of life plan.
- With regard to the provider of care services, half of those who answered said that they had a choice of provider.
- Where the person with dementia had spent time in hospital comments about their experience included food just being put down and left which resulted in the person not getting anything to eat.
- Of those who indicated that they have opportunities to talk to other people in the same situation as themselves, comments included:-
  - ❖ For the person with dementia to attend a Day Centre for one day a week for him to mix with different people.
  - ❖ To be able to talk to carers in similar situations would be very useful as ideas, methods used, etc., could be swapped
  - ❖ Have had very good chats with the psychiatric nurse who gave us some good advice which stood me in good stead
- Carers were asked if there was anything else that they would like to do such as attending events and classes at local centres:-
  - ❖ If I want to go out for the day I would like him to be able to go until about 6.30 and then I could pick him up
  - ❖ I only go to events where you can both attend. I do not have time to attend classes.

- ❖ Would like to attend classes but not been possible until recently when I have managed to place my wife in day care
- The following additional comments were made by carers:-
  - ❖ Being able to come to the memory clinic to discuss any problems we may have
  - ❖ Although there are a lot of people waiting to help and a lot of information that is available, it can be a bit of hit and miss on whether you get all the support you need.
  - ❖ Perhaps when a person is first diagnosed with dementia somebody should identify who the carer is going to be and make sure they have a copy of something like the excellent "Dementia Guide" published by the Alzheimer's society.

### **Key findings from interviews with Carers of a person with dementia who has recently passed away**

- A questionnaire was produced for use with a very small sample (3 people) to find out about end of life services for people with dementia. The interviews were undertaken by staff from the Carers Centre.
- The length of time that people had suffered from dementia prior to death ranged from 2years to 10 years. Of the three responses two people were in a care home and one was in hospital.
- End of Life Care Plans were in place for two of the three people, and in both cases the wishes of the person with dementia were carried out.
- When asked about support (including for the carer) in the final days, this was provided by care home staff, NHS staff, the Alzheimer's Society, GP, Mental Health Team, District Nurses and a Priest.
- With regard to general comments one person indicated that getting a diagnosis was very hard as letters from the GP were sent to the person they cared for so diagnosis was not made until they were in



hospital for another reason. They also found out about Alzheimer's Society far too late.

## Key Findings from the General Public Questionnaire

The questionnaire was designed to test out people's thoughts and understanding about dementia and the draft Strategy, and was completed by 78 people.

The first section of the questionnaire was to get a picture of people's understanding of dementia and on the whole most people have a good knowledge of what dementia is, how it can be treated, and the standard of life that people with dementia can have.

It also asked about people's thoughts about what people with dementia should be able to do including:

- Continue to live alone
- being able to continue to work for as long as they are able
- continue to drive for as long as they can
- Use technology to enable people to stay safe in their home
- Have a single point of contact for their dementia care

Most people agreed with all of these statements. The only exception was that people with dementia should continue to live alone which had an equal split between agree, disagree and not sure.

People were then asked for their thoughts on the following statements:

- **People with dementia should be involved in activities in the community** – most people agreed with this statement
- **It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home** – most people disagreed with this statement
- **There is little or no benefit to be gained from telling someone they have dementia** – the majority disagreed with the statement or were not sure about it.

- **People who have just been diagnosed with dementia are unable to make decisions about their own care** – most people disagreed with this statement
- **There is no point in trying to talk to people with dementia as they won't be able to understand** – most people disagreed with this statement

With regard to the Prime Minister's Dementia Challenge to create dementia friendly communities, which was launched in 2012, people felt that dementia friendly communities will be places where:-

- People with dementia are supported to remain active and included members of their communities
- People will have increased understanding and awareness about dementia and how to support individuals with dementia.
- To support individuals living with dementia and their carers to maintain their independence for as long as possible
- People with dementia being treated as valued members of society
- People with dementia and their carers feel comfortable in their local environment (shops, leisure facilities, etc.)
- People who work in the local community are trained to respond to the needs of people with dementia and do very simple and practical things that can make an enormous difference
- Implementing simple steps to help people with dementia such as slow lanes in supermarkets and banks
- Support from befriending groups to help people with dementia do the things that they want to

The final section asked about the Strategy itself. It listed the aims for people with dementia in Sefton and asked people to rank them 1-9.

The top five selections were:-

1. People with dementia should be diagnosed in a timely way
2. People with dementia are treated with dignity and respect
3. People with dementia get the treatment and support which is best for their dementia and their life
4. People with dementia will have help in planning for their future health and care needs through a co-ordinated health and social care service.
5. People with dementia's wishes with regard to end of life will be respected

Respondents were then asked to rank the Strategic Objectives in the Strategy from 1-5. These are the results:-

1. Timely diagnosis, appropriate treatment and involvement in care plans
2. Support to live independently for as long as possible, and to make decisions for myself
3. Inclusive and dementia friendly communities
4. Information, advice and support for people with dementia and their carers
5. End of Life Services, ensuring a peaceful and pain free death in the place of choice.

## Gaps identified from the Consultation & Engagement Process

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### Early Onset Dementia

There is currently very little information available about the numbers of younger people (under 65) in Sefton with dementia.

Getting an accurate diagnosis of dementia can take a very long time for people under 65; often due to lack of awareness that dementia can happen in this age group. Medical professionals often misdiagnose them as being depressed, experiencing relationship difficulties, suffering from the effects of stress or, for women, it may be put down to the onset of the menopause.

Younger people with dementia will face different issues, especially if they are still working when they receive a diagnosis. They may face discrimination at work and have to give up work earlier than they would like. As the population ages and the retirement age increases, it is more likely that more people will be diagnosed with dementia while they are still in work.

Dementia care services are usually designed for older people. Some dementia services have a minimum age criterion of 65 and even if services accept younger users the type of care they provide may not be appropriate. This means that younger people with dementia may have to travel considerable distances to access appropriate services or they may be left without the support they need.

It is essential that younger people with dementia have access to a range of specialised services that address their particular needs and enable them to live well with dementia. This should include not only health and social care services, but also wider services that promote their wellbeing such as financial advice and support to remain in work should they choose to do so. Many will have significant financial commitments such as a mortgage. They often have children to care for and dependent parents too.

Their lives tend to be more active and they have hopes, dreams and

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ambitions to fulfill, up to and beyond their retirement.

The contribution of family members and carers is often very important in helping to reach a correct diagnosis in this age group. Many people say the first sign that something was wrong was that the person 'didn't seem quite themselves' or they started to make mistakes at work that didn't fit with their usual performance



## Dementia and Learning Disability

This was raised at the Open Space and Innovation events during discussions around the topic “Promoting Diagnosis”.

Dementia generally affects people with learning disabilities in similar ways to people without a learning disability, but there are some important differences. People with a learning disability are at greater risk of developing dementia at a younger age – particularly those with Down’s syndrome where one in three develop dementia in their 50s. People with learning disabilities:-

- often show different symptoms in the early stages of dementia
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia
- may already be in a supported living environment, where they are given help to allow them to live independently
- may have already learned different ways to communicate (e.g. more non-verbal communication if their disability affects speech)
- will require specific support to understand the changes they are experiencing, and to access appropriate services after diagnosis and as dementia progresses.

There is no evidence that dementia affects people with learning disabilities differently to how it affects other people. However, the early stages are more likely to be missed or misinterpreted - particularly if several professionals are involved in the person's care. The person may find it

hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change.

It is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored

Studies have shown that the numbers of people with Down's syndrome who have Alzheimer's disease are approximately:

- 1 in 50 of those aged 30 to 39 years
- 1 in 10 of those aged 40 to 49 years
- 1 in 3 of those aged 50 to 59 years
- More than half of those who live to 60 or over.

With regard to those people with learning disabilities other than Down's syndrome studies suggest that approximately:-

- 1 in 10 of those aged 50 to 65
- 1 in 7 of those aged 65 to 75
- 1 in 4 of those aged 75 to 85
- Nearly three-quarters of those aged 85 or over.

These numbers indicate a risk about three to four times higher than in the general population. At present we do not know why this is the case and further research is needed

## Information and Background

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The refreshed Dementia Strategy and consultation has been developed by a multi-agency working group including officers from Sefton Council Business Intelligence and Performance Team, NHS South Sefton CCG, NHS Southport and Formby CCG, Sefton CVS, Mersey Care NHS Trust, Alzheimer's Society, Sefton Pensioners Advocacy Centre, Age Concern, Sefton Partnership for Older Citizens, One Vision Housing, Care Homes Association, Liverpool Community Health NHS Trust and Southport & Ormskirk Hospital NHS Trust. The group is chaired by the Cabinet Member for Adults and Health, Councillor Paul Cummins.

### Where we started from: Sefton Dementia Strategy 2009 – 2014

Following publication of “Living Well with Dementia: A National Dementia Strategy” which was published in 2009, a multi-agency group was formed to deliver a Sefton Dementia Strategy. This group comprised officers from NHS Sefton, Sefton Council, Mersey Care Trust, Sefton Carer's Centre, Sefton Pensioners Advocacy Centre and Sefton CVS and also included GP representation.

The National Dementia Strategy provided a strategic framework which local commissioners and service providers could use to deliver quality improvements to dementia services and address health inequalities relating to dementia; provide advice, guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services; and provide a guide to the content of high quality dementia services.

It was recognised that the National Dementia Strategy would take up to 5 years to implement. The national strategy included 3 key themes, namely:-

- raising awareness
- early assessment and diagnosis and
- living well with dementia

17 objectives in support of the themes had been developed to ensure local access to services for people with dementia and their carers, and five key priorities for action in Sefton 2009-2012 were identified as follows:-.

- Improving Public and Professional Awareness
- Early intervention and diagnosis:
- Improved community support services;
- Improved quality of care for people with dementia in general hospitals:
- Living well with dementia in care homes

Work was undertaken to review services for people with dementia and develop priorities for future investment. A consultation exercise was undertaken in 2008 and a carers' survey undertaken in March 2009 formed part of the review process to assist Commissioners to determine future investment priorities and identify opportunities for service re-design.

The Strategy was monitored and reviewed by the Sefton Partnership for Older Citizens, which in turn reported to the Healthy Communities and Older People sub-group of the Sefton Borough Partnership.

## **Living Well with Dementia: A Strategy for Sefton 2014-2019**

Sefton's current strategy for Dementia runs from 2009-2014 and there is therefore a need to refresh this in order to reflect changes in national policy and guidelines and the changes in structure to health services in Sefton.

Dementia has been identified as a Government priority and there was an additional marketing campaign, the launch of an online training tool and a dementia promise during April 2014.



Sefton is also currently refreshing its Carers and Older People's Strategies, the consultation on which has recently taken place, and this provides an opportunity to ensure that the Dementia Strategy is linked to both of these Strategies.

## The Consultation and Engagement Process

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This report brings together the feedback from the communities of Sefton and sets out the key points and recommendations that have emerged through our conversations with the public and stakeholders over the recent months.

A multi-agency working group including officers from the two CCGs for Sefton, Sefton Council Business Intelligence and Performance Team, MerseyCare Trust, and the Voluntary and Community Sector developed and progressed the consultation and engagement process for the Strategy. The group is chaired by the Cabinet Member for Adults and Health, Councillor Paul Cummins.

### What are the aims of the engagement process?

The aim of the consultation is to gather the views of people with dementia and their carers on the realities of living with dementia, to understand how their needs are being met, what gaps they have encountered and their views on improving services across Sefton.

The outcome of the process is the development of a final version of **Living Well with Dementia: A Strategy for Sefton 2014-2019** which will inform the future planning, commissioning and delivery of services for people with dementia and their carers in Sefton.

### Engaging Sefton's communities; what we did and why

The Steering group developed the proposed methodology for consultation as the representatives from the groups that work with people with dementia have experience about what approaches would work best.

Care was taken in identifying the methods to be used to consult with people who have dementia and their carers. There is no “one size fits all” approach as each person is different, will interact differently and traditional approaches may not be suitable. Guidance from the Dementia Engagement and Empowerment Project (DEEP) suggests approaches including small group discussions using pictures to help people connect with the discussion topic, visual aids to help people remember questions i.e. noting them on a flipchart or post it note, and using creative approaches to reflect views such as making collective pictures.

Taking on board the need to tailor consultation to specific groups, separate questionnaires were developed:-

- A questionnaire for people with Dementia
- A questionnaire for people who care for a person with Dementia
- A questionnaire for carers who have recently lost a person with Dementia
- A general questionnaire to collect the public’s perceptions and understanding of dementia

Two Open Space and Innovation Events for people, organisations, groups and providers of services were held. One in Southport on 1<sup>st</sup> July 2014 and one in Bootle on 3<sup>rd</sup> July 2014. The purpose of the events was to enable the sharing of views, thoughts, ideas and experiences about how together we can make a difference to the lives of people living with Dementia and their carers.

## How did we engage?

### Open Space Innovation Events

In order to find out about people's experience of dementia and living well in Sefton a wide range of people, organisations, groups and Providers of services were invited to come along to two Open Space and Innovation Events. The events were held on Tuesday 1st July 2014, at The Atkinson, Southport and on Thursday 3<sup>rd</sup> July 2014 at Bootle Town Hall. People could drop in and out of the sessions any time between 9.30 a.m. and 12.00 p.m. to share their views, thoughts, ideas and experiences about how we could work together to make a difference to the lives of people living with dementia and their carers.

61 people from a wide range of organisations attended the two events.

What is an Open Space Innovation Event?

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*Open Space – Innovation Events* enable people to drop in, join a discussion, listen to others within an 'Open' agenda and the 'Space' to share ideas and create solutions.

There is no preset agenda other than the topic previously agreed and the time allotted for the meeting. From the start of the event until the agreed end time people meet in groups to discuss and make recommendations for action which they consider are relevant to the specific issue – in this case improving the lives of people with dementia and their carers. A facilitator was available for each topic to guide the discussion and a scribe took notes of what was discussed.

Three discussion areas were agreed. These were:-

- Promoting diagnosis and supporting people to live independently
- Information advice and support for people with dementia and their carers
- Creating dementia friendly environments and communities across Sefton

In addition a Dementia Awareness/Dementia friend's area was available to give people the opportunity to find out more about dementia

People attending the sessions were free to move between the discussion areas to ensure that they were able to put forward their views on all the topics.

## What did the consultation tell us?

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### Open Space and Innovation Events

Discussion took place across three topics and participants were able to move to different discussions as they wished:-

Three discussion topics were:-

- Promoting diagnosis and supporting people to live independently
- Information advice and support for people with dementia and their carers
- Creating dementia friendly environments and communities across Sefton

The following comments came out of the discussions on each of the topics:-

#### [Promoting diagnosis and supporting people to live independently](#)

##### Southport Event

- **Down's Syndrome:-**
  - Early screening for dementia for children/adults with Down's Syndrome – dementia is statistically prevalent in people with Down's Syndrome and is being diagnosed more.

- Barriers to diagnosis include lack of information, lack of awareness for professionals, carers and families and general Practitioners not engaging.
  - Carers are more likely to spot early signs of dementia in people with Down's Syndrome and thus the relationship between the carer and the General Practitioner needs to be stronger and based upon mutual respect and trust.
  - If diagnosed early treatment can slow down the condition.
  - There have been no issues to date of people with Down's Syndrome who are cared for going missing from home as far as anyone in the discussion was aware.
- **Assisting people to live independently:-**
    - A decrease in funding of packages of care may impact on people being able to live independently.
    - Important that for people with dementia who are attending hospital for treatment there is no delay for their discharge as long stays often have a negative impact on the mental wellbeing (effects them cognitively).
    - Needs to be more community based health services to maintain people in their homes for longer
    - Currently no way of giving intravenous treatment for more than twice a day – more cost effective to invest that resource in the community rather than potentially blocking hospital beds.
    - Visits to people in the community need to be for at least 30minutes and although this is currently the practice in Sefton this needs to be monitored effectively through contracts and commissioning to ensure compliance.
    - Continuity of carers going to see people in their homes – this is generally provided by commissioned agencies and there can be a high turnover of staff which does not allow for service users to build up a relationship/connection with their carers and this can add to their confusion/distress.

- Meaningful day services for people with dementia - loss of day centre provision from the Local Authority. People with dementia need activities that stimulate them. Sefton is currently looking at how it provides day care.
- Services are still a postcode lottery based upon what different agencies/trusts provide. North/South divide in terms of services available.
- Need more home care support services, particularly out of hours/night-time.
- Wider impact of those with dementia on those around them; carers, friends, family etc.
- Better use of new drugs that becomes available on the market.
- Home adaptations and accommodation design are important. Currently One Vision Housing is working on a design brief as part of their community based accommodation update/refresh that is dementia friendly. Has to be non-intrusive.
- Need to build dementia friendly considerations in to our everyday capital schemes. Taps with cut off sensors to prevent sinks/baths over flowing.
- More co-operation and integration of services.
- Better signposting for all.
- Managing risk to help people live independently.
- Greater awareness amongst professionals around roles and responsibilities – Who does what?
- Whole person approach – services need to be flexible to meet the needs of individuals.
- Understanding the General Practitioner's referral process.

- How do we support the support networks? Mutual support services/networks based upon people's experience.

- **Promoting diagnosis**

- People's reluctance to get help in the first place due to stigma associated with mental health. Also people and families can often be in denial about the condition and try and cope as best they can.
- General Practitioners – difficult to diagnose due to memory loss being often a symptom of other physical problems being presented at surgeries. General Practitioners tend to deal with the physical diagnosis first so often the dementia diagnosis is either lost or delayed.
- Need to promote the importance of getting early diagnosis – drug treatment and services available. Early diagnosis needs to be publicised as positive.
- More needs to be done on awareness raising to improve the public's perception of dementia.
- Negative media has had an impact on people not wanting to be diagnosed in case then end up in a home that turns out to be poorly managed with poor practice habits. – Needs more positive press.
- General Practitioner training and awareness raising – some General Practitioners are reluctant to diagnose until the patient and family reach a tipping point.
- General Practitioner diagnosis needs to be consistent in their approach – some are overzealous and others too cautious – training to help assist.
- The physical impact on health of people suffering with dementia needs to be recognised.
- Being taken out of routine environment tends to highlight the issue and it is then that professional's, carers, family can help to identify and seek an assessment for diagnosis.

- A significant amount of people remain un-diagnosed.
- Professionals need to be more aware of the signs to look out for. 'Every contact counts' approach. Part of staff core knowledge.
- Professionals need to have the confidence to identify and broach issues with the individual and families (training).
- Need to investigate how local businesses can help to identify those perhaps not yet diagnosed and who do they raise this with and where does it go to?
- Need a similar campaign as Cancer in terms of the number of people dementia affects and the nature of the illness. Current campaigns around dementia have portrayed a negative image of the services received.
- Need to raise awareness that it is not just an older person problem but is wider than that. Start to teach as part of a general life course awareness raising in schools around the topic.
- Posters in prominent areas such as super markets.

The following were discussed as possible actions to take some of the above forward:-

- One Vision Housing would like a link in to Adult Social Care Services to understand the access criteria and what is available.
- Need to identify where awareness raising training currently take place in the borough?
- What level of training do Police officers have and in terms of places of safety could they be made dementia friendly?



- **Services**

- Memory Clinic – based in the North of the Borough and linked in to the Alzheimer’s Society. Could the service perform dementia assessments as an outpatient /community based service to avoid delayed discharges in hospitals? Is there evidence that this is a successful service, with appropriate waiting times and easy access?
- When someone is diagnosed they need to have a link with Alzheimer’s Society to ensure someone available to be present at the diagnosis to help answer questions and to offer support.
- All referrals come from General Practitioners.
- Support with early memory loss, post diagnostic work, signposting, information giving.
- Agencies advise that they struggle to get people with severe learning difficulties assessed by Memory Clinic.
- Pharmacists – What do local Pharmacists do in terms of identification of dementia?
- Walk In Centres – What do local Walk in Centres do in terms of identification of dementia?

The following action is proposed with regard to the above:-

- Mersey Care Learning Disabilities to feed in to Dementia Meetings

## Bootle Event

- **Assisting people to live independently:-**

- Need to consider the impact on the family and carer(s) around the individual as they offer the most support and their health is just as important to maintaining people in their own homes longer. Also need to consider their social isolation as they often lose touch with people around them when they become the main carer (issues such as lack of sleep, increased stress levels, becoming agitated).
- Friends and family avoid people with dementia due to a lack of understanding of dementia.
- Cross generational work – shift in culture – young people and older people working together.
- More work around understanding changes in behaviour as a result of dementia.
- Immerse the family in what is happening.
- Easy access to Information, advice and guidance.
- Information, advice and guidance following diagnosis.
- The assessment process needs to be more holistic and should involve other agencies who provide services as well as the person, their family and carer.
- There needs to be a structured pathway following diagnosis with other agencies involved in agreeing, developing and supporting that pathway – information, advice, guidance, face to face, advocacy, networks and groups etc.
- More preparation work with families/carers around planning for the future.
- Need to consider managing end of life treatment for those with dementia, for example managing pain medication.

- At what stage do we decide when a person can come and go as they please when suffering with dementia? Managing the risk. Awaiting judgement on deprivation of liberty.
- Use of dementia friends.
- Currently services are available based upon postcode and this is not equitable.
- What is available – community equipment? Helps people to manage longer.
- Opportunities for people to meet and talk with similar people who are experiencing dementia.
- A mobile night visiting service that also offers a sitting service during the week.
- Need to consider those with dementia who have no family or carer.
- Need to revise/review the virtual ward model.
- Need to consider how we wrap the care around the individual and their carer.
- Need a 24hour 7day a week contact service for health and social care.
- Difficult to get an emergency respite night.
- Keep the individual active and improve availability of low level interventions.
- Health and Social care fragmented - confusing to both the public and professionals.
- Need a key worker for continuity when dealing with family and those with dementia.

- Doing nothing is not an option – increasing elderly population with more complex needs in Sefton matched by decreasing resources.
- Transport is an issue for people being able to access day care provision.
- Diagnosis rates for dementia are around 50% of what is believed to be the actual figure.
- **Promoting diagnosis**
  - Difficulty of accessing services as some General Practitioners diagnose only the physical health problems and overlook the potential mental health issue of dementia.
  - A general awareness raising campaign like the one rolled out for Cancer that reaches most people and training as part of a core set of skills for all professionals with regards to dementia.
  - Families and carers more likely to spot signs earlier. They need to know who they can speak to i.e. the persons General Practitioner about their concerns.
  - Need to look for the signs of people putting in place strategies and coping mechanisms to mask their illness and prevent early diagnosis.
  - Dementia needs championing positively in terms of early diagnosis. Too much bad press.
  - Still perceived as a memory issue.
  - Specialist General Practitioners with a clear understanding of dementia being available to colleagues for advice and guidance?
  - Feedback from families is that they would have appreciated advice and guidance earlier.

- Early diagnosis can lead to years of improved quality of life.
- Need to remove the fear or stigma of going in to a care home for those most needy.
- Sharing information and improving communication.
- Improving the negative image/perception of social care i.e. all they do is put you in a home.

The following action is proposed with regard to the above:-

- Post-diagnostic support available in North of Borough but not the South (Alzheimer's Society)
- **Services**
  - Health and Wellbeing Trainers – work with community, operate out of Burlington House via Sefton CVS, work around social isolation, offer training, link with some General Practitioners (those willing to engage), part of the Virtual Ward.
  - Memory Clinic – How many people do they see?
  - Community Practice Nurses – need to be trained and made aware as to what is out there.

The following action is suggested with regard to the above:-

- There needs to be a mapping exercise of befriending services in Sefton. There are currently long waiting lists – anywhere from 12 weeks to 6 months..

Southport Event

• **Support for People with Dementia and their Carers**

- People are isolated – couples live on their own and say they are coping. Are people struggling because they don't want help or don't know where to go. People just muddle along until they are in a crisis situation
- Husbands/wives tend to think it is their role to be carer, for better or worse and don't seek support - the Label "Carer" inhibits people to get help because they are a husband or a wife. People need to be a husband or wife and understand that other "SUPPORT" is available - it is ok to have support. People need to understand they won't be a good carer if they don't get support
- Some people are private and don't want to show they are vulnerable
- People say Social Care hasn't worked for me after a bad experience and aren't prepared to try anything else
- Some family members are controlling and abusive, is this conscious or does it come after years of caring and you don't realise your behaviour has changed
- The main carer often sees other family members as interfering and pushes them away. Other family members or friends trying to get help are kept away by the carer (husband or wife)
- It often gets to the point where the carer can't look after themselves. If a carer becomes ill and there are no family members around they can become a crisis

- People need to get over the stigma of being a carer. Maybe we should say someone is not “THE” carer but “A” carer, part of a supporting care team. People don’t like the word carer, they are a family member and we should use a whole family approach
- People sitting services are needed
- People miss out on the bigger picture; a little bit of help can make all the difference. How do you get a little bit of help? Where do you go?
- Money – Paying is an issue if you don’t get the service you are paying for
- Professional carers get people up from 11- 5pm so care isn’t tailored, people want to be up 6-10pm ish. Commissioned services are dictating delivery. Staff can’t do later because of block contracts, so people don’t want service as they can’t deliver what is needed. There is an intensive time in the morning and evening when lots of staff are required but not available
- Respite is only every 6 months, there needs to be a shift, there needs to be financial proof that giving a carer £1000 to have respite will save money in the long term by keeping them well
- 2 main barriers – hard to reach holding onto role as carers and the service options available (home care or care home) are not suitable
- Couples protect or mask each other
- Family members don’t know what signs to look for (no food in cupboard)
- Health professionals need to be harsh and tell people “you are not helping”
- GP’s play a pivotal role

- Support need to produce an “at risk profile” from demographics – over 70, no children in the areas, possibly visit GP regularly because they are lonely or don’t visit at all. These should be on a high risk register and on GP’s radar
- Organisations such as affordable warmth go into people’s houses and see risks, they should pick up on these and be able to feed them back, anyone gaining access to someone’s home should look for risks
- We should see the person not the illness, people have a range of illnesses and they shouldn’t be labeled. Medical staff often don’t worry about other ailments such as heart conditions and just deal with the dementia, dementia often masks other conditions or it might not be dementia but similar symptom
- People don’t want to admit they have a problem - If they get help first it can be better
- People need support before diagnosis as this can take a long time
- Care home staff can see deterioration over time but families can’t see it and won’t accept – a lady took her mother to Spain against advice because she thought she was ok and she was very confused which shocked her daughter who then booked a cruise
- Gentle conversations need to be had with families to build confidence about stigma
- We need to build support around the family unit
- People are angry, confused and frustrated, the main carer also has their own medical needs but no time and no one to speak to
- We need to speak to people at the right time and have tougher conversations in a supportive way and this issue is not going to go away



- We need to recognise carers as this is how we society is going to cope
- There is bad press about paid care - and paid care is open to abuse
- We need to give skills to older men re cooking / washing etc as they will never have done them before, change cultures so they can offer support
- There should be behaviour risk management
- We need wrap support round people and maintain anyone already around then add to it
- We are all carers at different levels at different times in our lives we might need to make small adjustments to our lives but it's about loving someone, duty, responsibility, it shouldn't be because we have to but because we want to. Some people don't have this view due to expectation that it is the NHS responsibility, where has love gone? There needs to be conversations that it is your responsibility, there has been a culture shift of people becoming selfish, they ring an agency and their job is done, people need to take ownership and we assist no do for.
- We recruit by behaviour now and we should be assessing the behaviour of families, we need to understand people's attitudes before they are assessed, we need to separate those who feel care should be free and believe it

- **Information and Advice**

- Where should people go for advice? Dementia agencies, pharmacists, road shows, Age UK, SAGA (over 50's, silver surfers, have DOB to mail shot you)
- People who get lots of information in the post don't read it and just bin it

- Organisations need to say the same thing, they need to give a consistent message and advice
- Organisations and charities should work better together and not be in competition with each other (at the Southport road show 3 different organisations were recruiting befrienders and competing against each other). Organisations should, join up, not be competition. Commission differently, work better together, pool resources, work differently, pool befrienders and sitters etc
- Information should all be put in one place and be accessible. Someone can show you how to use the information as long as it's all in one place. There should be simple stuff on the web not just diagnosis stuff
- There needs to be a process in place not just a directory, a flow chart of long term condition info and advice. The Sefton directory just confuses people. We need to lay out the process families will go through
- More needs to be done at diagnosis, don't just diagnose and leave, show pathway and where to go
- Use mosaic to see how people would like to receive information
- One Vision Housing has given a pack to 1000 residents. We need to learn from this process and experience
- One Vision Housing have used the house of memories approach and this should be replicated
- There should be core information for all, if you wait till the GP tells you, you won't get it All organisations should agree basic information, at the minute information is confused and people don't do anything until it's too late
- There is a mismatch between care services language and public language, language is important (service user / client – all misunderstood) (frail elderly, Elderly & mentally infirm – degrading) People don't want to be labeled

- There should be information on early signs and symptoms and how to get help
- We shouldn't use negative labels
- A key message must be early diagnosis, if you're worried about your memory see your GP. How do we raise awareness – early diagnosis
- People are swamped with information, advice and competition between charities
- Leaflets and shops etc should use assessable information and pictures, less info & easy read (this is important for low level adult literacy, EASL too)
- People are coming to use the shops as they have more confidence, time to pack, go slow isle, people wear a badge if you need help
- Information in shops rather than GP's is good
- We need to share information, but let the individual store info and share it with who they want so no data protection issues
- **Other issues**
  - We need to support people to share their experiences with the strategy development group so we can get under the skin of issues
  - We don't shout loudly enough about carers. Sefton is a very caring borough but we do not champion this, we should have pride in carers, value them
  - Lots of carers don't recognise they are carers yet they have bought into the situation
  - This is just about us living as we will all go through it at some point with a friend / relative or ourselves

- Organisations and commissioning work in boxes so it can never be person centered
- Society has unrealistic expectations – some people can't be bothered caring for family members, we should champion great families, self care, saving money for later life care, having the human touch and listening to people. We need to reset language as we are speaking 2 different languages
- We only work at the tipping point but need to move to prevention
- We could have a Sefton version of a time bank and celebrate skills and gifts
- People with dementia have gifts and skills to share in communities and just need support. We need to get people out into the community
- We should listen to individuals but encourage them to live well in their community
- Do neighbourhoods still support each other, if it's a stable area then yes but if not no, people don't know where this support is happening or how to replicate it
- Housing providers have a responsibility to design friendly communities with low fences, walking paths etc where community champions can be based
- A block of shops has done its dementia friends training but a stumbling block is getting them to write action plans (there needs to be a light version for small businesses) – there's pop up pubs, badges, training, GP lead, memory prompts
- Faith communities – how helpful are they? Churches are big but we don't know what they are doing we need to grow and join together
- Is it dementia friends or People friendly? Family friendly, respectful, elderly friendly (MH, LD) we should be a people friendly borough running a campaign on dementia / LD etc we

should be disease or condition friendly. Champion great families, communities, Sefton a great place to live

- We need to celebrate positive stories and messages like cancer, there needs to be positive marketing and mindset. We need to show its not all over just because you have dementia – there are lots of funny stories, it's not all doom & gloom
- Because of the pattern emerging in the UK, China have passed a law 20 years before its needed making it illegal to abandon an elderly relative
- Families are not making the best decisions because of money, they are protecting their inheritance, and there have been cases of people being locked in cellars. We need to talk honestly about money – people don't like to talk about it because it's embarrassing but people wouldn't demand a paid for taxi from M&S so why do they expect it from A&E? We need to set out the costs in plain English and have discussions
- We need a “right & wrong” is this the way to treat people campaign, like moral dilemma story lines / cartoons which one are you
- There was a couple he was in his 80's and her in her 60's they used all of their savings on his care, she had no money left after he died to look after herself, is this fair?
- Some people don't want relatives back after they've been in care or hospital and they do things so they can't move back, last week a man dumped his mums furniture so she couldn't move back to her home as he'd moved in and didn't want to share
- People dump relatives before they go on holiday, we need to start involving the police if this happens
- We need to speak the same language and not pass the buck from one organisation to the next deal with it, we need to get our ducks in a row as a whole team

- If the system falls over, start again, people play the system and its a cycle
- We need to assess how efficient people are being at managing their own health, find out who is inefficient and have conversation with them, private industry would know who they are and do something about it
- We need to keep people on track on a pathway with one care plan the we all feed into

## Bootle Event

- **Support for People with Dementia and their Carers**

- It has takes a long time to get a mental health assessment for a lady being aggressive – there was lots of red tape, her family were reluctant to do anything or admit there is a problem, 1 month on and still there has been no action, time scales around assessment need addressing. Once a risk has been identified I would expect the issue to be escalated, as would be the case with a safeguarding pathway referral.
- Issues are that people live on their own and wait until they reach crisis point – they then call the GP who rings the rapid response team, often they have an infection (such as a water infection) this can make them more confused and increase the risk of falls. People get up to 4 care visits per day bu7t nothing at night making night falls a risk, they often get up a lot at night, these people don't need to be in hospital but are not safe to be at home alone, people are placed in nursing homes for a few weeks and then have a trial at home to see if they are ok.
- If the main carer is ill and goes into care for safety, them a double placement is needed, the CERT provide 72 hours of emergency cover but sometime this has been known to last 2 weeks.
- People often ring and say they are not coping but this is not medical it is social; social services are very slow, why? Is the system clogged up?

- The CERT do the following – refer to Chase Hays for 2 weeks rehab (there are never enough beds which causes a back log), advocacy, befriending and help with shopping, housing support if homeless, make phone calls for people or give numbers (e.g. Carers Centre), take people to the carers centre
  - The CERT is a multi disciplinary team of Nurses, GP's, Physio, OT, Memory Clinic
  - We shouldn't see someone with dementia in isolation of their support network
  - Anyone with dementia needs support - It financially makes sense to support
  - In the past people have lived for up to 40 years in care, but thresholds are increasing so better if people live longer at home, this is better because their surroundings are familiar.
  - We should support people who care to do it for longer
  - We should keep people at the lower end of the spectrum as long as possible
  - Families need support for long term conditions
  - Dementia "Friend" – they are not a carer or an expert just a friend, this language is very good
- **Information and Advice**
    - There is lots of information available

- The CERT (Community Emergency Response Team) –People don't know who we are, we need to raise the profile with professionals as they do the referrals, we need to work hand in hand with social workers / services to pick up the slack
- Self funders do not want to pay for care (they say why should I pay) so pull out after 2 weeks (not 72 hours) then they are in crisis again and it's just a spiral.
- The CERT signpost to luncheon clubs but there are not a lot around
- The CERT do not use a PC but use hard copy directories
- One vision are holding a focus group together looking at peoples experience
- Small changes to environment can make a difference (housing & communities)
- There is lots of information around – but how do you know? You only know what you know
- Information should be not all IT based as not all on PC
- Information should be at GP's, Post office – Places where people go, also we should inform the people who work there and educate them about what groups are available locally
- We do not need to invent anything it's all there it's just about getting hold of it
- Information shouldn't just be with GP's as people are anxious at Dc's and don't read notice boards, we need to target people
- We also need to target carers – the free press is good
- People can live well and extend life so not all negative
- We need champions who are living well to promote in the media
- People don't know what to say so don't ask in case they get it wrong, saying anything is the right thing saying nothing is wrong



## Creating dementia friendly environments and communities across Sefton

### Southport Event

- Sefton Careline offers assistive technology to help people stay at home – alarms, monitoring, pressure pads, fall monitoring based on individual needs.
- Changes in benefits are affecting people with dementia and their carers
- Wander alerts/alarms linked to central point to advise when people go out on their own
- There is CCTV monitoring in sheltered schemes – but only in public areas for security purposes.
- CCTV monitoring of people with dementia in their homes – has privacy and human rights issues. Fine line between wanting to check person is ok and spying.
- Telehealth/Telecare is helpful – uses system like SKYPE so that professionals can contact patients to take BP readings, consultation on-line and results are sent to a central point.
- Danger that technology is replacing the personal touch which is important for people with dementia.
- We need to encourage people to do more for themselves – so they can get out of the house, build and maintain capacity and avoid social isolation.
- Early Stage Dementia – people worried about perceptions of them and it puts them off doing things for themselves – deteriorate much more quickly.
- Befriending Services are good – but over-subscribed. Do we need to identify who is providing them and encourage them to work together, identify areas where they are duplicating provision to enable them to reach more people over a wider area – need to promote volunteering.

- Use existing resources to widen help for people with dementia by training people up to become Dementia Friends – use SPOC/SPAC/VCF sector and also encourage public sector partners to become more active e.g. refuse workers being able to signpost people etc.
- Need better data sharing protocols between agencies to identify people with dementias. At the moment there are problems sharing personal data.
- Older People in general aren't accessing food banks – missed opportunity to identify those who need help.
- How do people know if shops/businesses are dementia friendly? No plaque or branding available and process to get some recognition is overly bureaucratic and needs one person to co-ordinate – off putting for small businesses
- Need to get public transport/taxi services on board – Dementia Friends Training.
- Community Leaders need to take ownership – encourage more DF areas.
- Need to change culture in neighbourhoods – build trust and encourage neighbourliness
- Safeguarding issues – where informal help is in place may be problems where people have memory issues in accusations of things happening that haven't actually happened. May put people off.
- Should we develop “informal neighbourhoods” rather than formal volunteering routes?
- How do we identify and help the “unwilling carers” who start off doing a bit but then end up as full time carers.
- Nursing Homes are seen as somewhere were “people are put” and don't come out of rather than somewhere that people might choose to

go for respite or short term care. Need to change perception and use them more as community facilities.

- Community Centres could be used as a catalyst to bring communities and resources together and work more collaboratively
- Education and awareness needs to have a more positive approach
- How can society move on to help people with dementia live well
- Dementia Friendly is of benefit to the whole community
- Needs a more positive approach to dementia – to make it less frightening using a more informal approach
- Is better planning part of the solution? Things like end of life planning, better information about changes in journey, etc.
- Need to make people with dementia “feel like people” rather than just focusing on condition.
- Approaches such as memory boxes, pop up shops, pop up pubs, music therapy, etc. are working well but heavily oversubscribed. Can we extend this further?
- How do we build up networks/communities that have been lost?
- Don't see people with dementia in isolation – need to keep the whole “unit” well in order to keep people out of hospitals and institutions if carers fall ill. Build carers into pathways.
- There are degrees of caring – people don't identify themselves as carers – just looking after mum/dad/partner/siblings, etc.
- There is a GP pilot currently running in one practice in the North and one in the South to identify carers from their lists.
- Dementia is the poor relation of mental health – it is a disease of the brain but is still often seen as taboo.
- Need to promote positive messages about living well with dementia – using positive methods and approaches.

- Need to encourage people with dementia to keep their skills – use them as positive role models.
- How do we identify those who haven't been diagnosed?
- The “face of dementia” is very negative – how do we get a more positive approach to tell people that it is possible to live well with dementia.
- Banks/Taxi operators are important to dementia friendly societies.
- Building Communities: can churches do more to bring people together.
- Hospital provides packs for people with dementia and their relatives – information sheet giving details of useful numbers plus leaflets for things such as memory cafes, etc.
- Too much time spent in hospital awaiting tests away from home – testing should be done in the community.
- Dementia Friendly communities – more information needed so that communities/stakeholders understand dementia and remove stigma/barriers, but key stakeholders need to be involved to take it forward.
- Independent Living schemes give a sense of community (Fernley Grange) but need to find ways of opening this up to the outside so that people get involved.
- Encourage volunteering as a way of avoiding social isolation.
- Top down approach doesn't work – needs to be community led.
- People on the ground need to deliver on Dementia Friendly Communities: District Nurses/Health Visitors, etc.
- Need to share good practice – how do we cascade information if we don't know what is going on? How can we join up the dots?

- Awareness raising of Dementia Friends – use all areas of organisation to identify dementia early.
- Pilot Dementia Friendly row of shops in Fylde Road, Southport – but not many people know about it – it's not advertised. There is no recognition that businesses are dementia friendly so how do people know that they are?
- There are barriers to becoming Dementia Friendly accredited that rely on one person taking responsibility for preparing an action plan for the area and reporting on every 6 months.
- Pilot in Fylde Road is good – but how do we extend this model to the rest of Sefton and other areas such as Churchtown, Maghull, Ainsdale, Netherton. All of these places are based around GP surgeries – could we use the surgery as the central point and include all the shops in the locality?
- Dementia is seen as an older person's disease – part of getting old.
- Southport Football Club hold regular Tuesday afternoon sessions for people with early onset dementia in conjunction with MerseyCare – including trips out to other venues such as Everton FC.
- Need to provide more education for young carers about dementia.
- Dementia Friendly is of benefit to the whole community as it provides a positive approach, is informal and less frightening.
- There is reticence about approaching people with dementia to offer help – how far does responsibility go? This needs a common sense approach.
- Pharmacies should be used more as an interface: medicine reviews, etc.
- Lack of diagnosis is a problem: earlier diagnosis would be helpful.
- GP's are reluctant to make a diagnosis or some are "over diagnosing". GP's need better understanding of dementia and the

services available to support people and their carers – memory clinics, memory cafes, memory boxes, etc.

### Bootle Event

- People make Dementia Friendly communities
- Communities need to understand dementia and offer support and challenge stigma
- Talk to people with dementia and ask what they want.
- Businesses can get an award of the national symbol for dementia friends, the Forget Me Not, but the process is quite bureaucratic. The symbol is allocated to an area and one person leads on the process to become Dementia Friendly. Can be done within existing resources and has benefits for businesses and raises standards for everyone. Nationally Tesco, Argos, M&S and Lloyds Bank Group are committed to becoming Dementia Friends.
- Some services are driven by technology – but this precludes people who are not IT aware – not just people with dementia i.e. Barclays banks taking service counters out of branches and using just machines.
- Services are moving out of communities, leading to loss of personal touch, awareness of where problems are or if somebody hasn't been seen for a while i.e. banks, post offices, etc.
- Transport needs to be improved – ring and ride service for older/vulnerable people bit like a “big taxi” service where people are collected and dropped off and then picked up again.
- Do people know what services exist?
- If people are diagnosed earlier it is easier to identify long-term support.
- Education is important – start early in schools to change “modelled behaviour”. This will help children to relate to family members and others who may have dementia.

- Need more inter-generational work to raise awareness.
- Could we become “Dementia Friendly Sefton” or “Bootle” or “Southport” or “Maghull”, etc. down to smaller localities such as “Birkdale Village” or “Ainsdale Village”.
- Could GP surgeries do more to co-ordinate communities to become Dementia Friendly?
- Use “pop up shop” in empty shop fronts to raise awareness.
- Families and Friends need support too.
- The Police/Fire Service can do more – help to identify where problems arise, particularly where people are isolated.
- Need more signposting so that people know where to get help and avoid hospital admissions.
- We need to be brave – fund smaller things to keep people out of crisis and the need for more expensive services.
- We need more “age friendly shops” including the “Take a Seat” project to provide somewhere for the old and vulnerable to sit in shops and businesses.
- Wigan Project (Hindley) for Dementia whereby £15,000 funding was provided and local businesses could pitch ideas (Dragons’ Den) for help for people with dementia such as swimming sessions, etc. Services had to be provided by local businesses. Staff in Morrisons supermarket set up a dementia café where people with dementia can come and pay £1.50 for coffee and cake and sit and have a chat and this has proved extremely popular. Can we extend to other local tea and coffee shops at times when things aren’t busy?
- Local Press needs to do more to highlight activities and events for people with dementia. This needs to be included in the Action Plan.
- Who get the ball rolling and take the lead on the Strategy. Need to get local people to want to take it forward.

- The development in Southport of the Dementia Independent Living facility for couples should provide an opportunity for Churchtown to become Dementia Friendly based around the Health Centre and the local shops.
- People with dementia could give talks to local businesses to give their perspective on what it's like to live with the condition – break down barriers.
- Pubs should become Dementia Friendly so that people with dementia can have some sense of doing what they would normally do. Could be a special hour when the pub would normally be quiet.
- Need to help people to keep working as long as they can after diagnosis if they are able to.
- Later retirement age (people having to work longer) –v- increase in number of people with dementia?
- Helping people to make changes to live well with dementia and as normal as possible for as long as possible.
- Diagnosis – then what?
- Not shutting people with dementia away but encouraging them to be part of the community.
- Care homes should become community hubs – have more interaction with the local community.
- Common interests/memories – people with dementia sharing with peers at places such as day centres, etc.
- Are the services we provide dementia friendly?
- Identify places where people know that they can go to get help if they need it (“safe havens”).
- Incorporate existing services into Dementia Friendly ones.
- Services/things need to join up and connected.



- Specific training needed for transport providers and taxi drivers.
- Lifestory network – developing services in Liverpool.
- Need better information – lots on physical disabilities but little for mental health issues.
- What is happening in Sefton? Need grass roots level approach.
- Need neighbourhood return scheme – volunteers helping to find people who wander.
- Lack of marketing – nobody knows what's out there.
- Need to support carers so that they don't lose their own identity.

## Questionnaire for People with Dementia

A Questionnaire was developed to be completed by people with dementia, to get their thoughts and opinions on their experiences and what would help them to live well with dementia.

The Alzheimer's Society were available to act as advocates to help people complete the questionnaires if required.

7 people completed the questionnaire

<b>Question 1 – Please tell us how you are completing this form</b>	<b>No of responses</b>	<b>%</b>
On my own	5	70
With a family member who is not my carer	1	15
With my carer	1	15
With a health and social care professional	0	0
Other	0	0

<b>Question 2 – How long ago were you diagnosed with dementia?</b>	<b>No of responses</b>	<b>%</b>
Less than one year	2	29
1-3 years	2	29
3-5 years	1	13
6-10 years	2	29
10+ years	0	0

<b>Question 3 – Who first realised that you were having problems with your memory?</b>	<b>No of responses</b>	<b>%</b>
My GP	4	57
Other health professional – as part of another health problem	0	0
I noticed myself that I was having problems	1	15
Somebody else (family/friends) noticed something was wrong	2	28
Other (please give details)	0	0

<b>Question 4 – How easy was it for you to get a confirmed diagnosis of your dementia?.</b>	<b>No of responses</b>	<b>%</b>
It was very easy – professionals listened	5	83
It wasn't as easy as it should have been – I had to convince professionals that there was a problem	1	17
It was very difficult – professionals dismissed my early concerns, and did not listen	0	0

<b>Have you received enough information about your condition</b>	<b>No of responses</b>	<b>%</b>
Yes	7	100
No	0	0

**What other information would you like? Please describe:-**

Felt time between being diagnosed and appointment at memory clinic should have been substantially shorter. Constant phone calls made to chase up.

**Please give details of any problems you faced or things that went well:-**

- Dolypazk tablets are very successful for me
- After working until I was 72 and being a production control manager and sales manager I found it difficult to fill my time in and not a great deal to motivate me
- Joining the Alzheimers society - thankyou

<b>Question 4 - Here are some things that people with dementia have said are important to them. Are they important to you</b>	<b><u>Yes</u></b>	<b><u>No</u></b>
In terms of my healthcare I will be able to be seen by the same person and not have to repeat my story over and over again to different people.	4	0
I will always be asked what I want, even when I find it difficult to answer.	5	0
My carer and I will have access to information and support throughout our journey, including services that will help me to stay well, safe and independent in my own home.	4	0
I will be able to communicate my likes and dislikes where ever I am	4	0
I will have a say in my end of life plan and will be supported to die peacefully in a place of my choosing.	3	0

**Question 5 – Now we would like to ask you about the services that you receive to help you with coping with your dementia**

<b>Did you have a choice of provider?</b>	<b>No of responses</b>	<b>%</b>
Yes	3	75
No	1	25

**What do you think of the services they provide?**

- Being cared for at home by my husband
- Excellent - my carer is my husband
- Good
- Alzheimers Society - Very good

<b>Question 6 – have you spent time in hospital?</b>	<b>No of responses</b>	<b>%</b>
Yes	2	29
No	5	71

If you answered yes please tell us about your time in hospital:-

- Not with dementia, other illnesses. Staff very busy. Needed more time for one to one
- Some was bad and some was good. I found the untrained staff didn't listen - they would put my drinks and food out of reach, the ones on nights couldn't answer bells - were rude and in one case when I asked for the commode the nurse said "you've a toilet in your room use it". I told her the specialist said I wasn't to use it. She said "what does he know" and she grabbed my arm and pushed me - I had a dizzy spell and I grabbed to stop me falling and she said "you bitch".

<b>Question 7 – Do you have opportunities to meet and talk to other people with dementia?</b>	<b>No of responses</b>	<b>%</b>
Yes	6	100
No	0	0

**Question 8 – Is there anything else that you would like to do such as attending events and classes at local centres?**

- Yes if possible
- Have some in Southport
- Social events organised by Alzheimers
- We already do
- No

**Question 9 – is there anything missing from these questions that is important to you (please tick all that apply)?**



No responses given





<b>Question 10 - Would you like the following people to have a better understanding of dementia?</b>	<b>No of responses</b>
Family	2
Friends	2
Employers	1
Hospital Staff	2
Social Workers	1
GPs	0
Care Providers	0
People who work in shops, banks, offices and post offices	2
Police	1

**Question 11 – details of any discussions you feel are important**

No responses given

**About You**

<b>What is the first part of your Post Code</b>		L23 1 23%	L30 1 23%	L37 1 23%	PR9 2 31%
<b>Are you:</b>		Male 5 71%	Female 2 29%		

<b>What is your age?</b>		<table> <tr><td>0</td><td>0%</td></tr> <tr><td>0</td><td>0%</td></tr> <tr><td>0</td><td>0%</td></tr> <tr><td>2</td><td>29%</td></tr> <tr><td>5</td><td>71%</td></tr> </table>	0	0%	0	0%	0	0%	2	29%	5	71%												
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5	71%																							
<b>Disability – Do you have?</b>		<table> <tr><td>Physical Impairment</td><td>3</td></tr> <tr><td>Visual Impairment</td><td>1</td></tr> <tr><td>Learning Disability</td><td>0</td></tr> <tr><td>Hearing Impairment/ deaf</td><td>2</td></tr> <tr><td>Mental health/ Mental Distress</td><td>2</td></tr> <tr><td>Long Term Illness</td><td>2</td></tr> <tr><td>Other:</td><td></td></tr> <tr><td>  Depression</td><td></td></tr> <tr><td>  Diabetes</td><td></td></tr> <tr><td>  Arthritis</td><td></td></tr> <tr><td>  Autovalve replacement</td><td></td></tr> </table>	Physical Impairment	3	Visual Impairment	1	Learning Disability	0	Hearing Impairment/ deaf	2	Mental health/ Mental Distress	2	Long Term Illness	2	Other:		Depression		Diabetes		Arthritis		Autovalve replacement	
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Yes	2	29%																						
No	5	71%																						
<b>Ethnicity</b>		<table> <tr><td>White British</td><td>5</td><td>84%</td></tr> <tr><td>White English</td><td>1</td><td>26%</td></tr> </table>	White British	5	84%	White English	1	26%																
White British	5	84%																						
White English	1	26%																						
<b>Do you have a religion or belief</b>		<table> <tr><td>Yes</td><td>5</td><td>71%</td></tr> <tr><td>No</td><td>2</td><td>29%</td></tr> </table> <p>5 people identified as Christian</p>	Yes	5	71%	No	2	29%																
Yes	5	71%																						
No	2	29%																						

## Questionnaire for people who are for somebody with Dementia

A Questionnaire was developed to be completed by people who care for a person with dementia, to get their thoughts and opinions on their experiences about their caring role. The questions mirrored those that were put to people suffering from dementia to see if the things that were important to people with dementia were also important to those who care for them.

20 people completed the questionnaire

<b>Question 1 – How long ago was the person you care for diagnosed with dementia?</b>	<b>No of responses</b>	<b>%</b>
Less than one year	1	5
1-3 years	9	45
3-5 years	1	5
6-10 years	8	40
10+ years	1	5

<b>Question 2 – Who first realised that person you care for, was having problems?</b>	<b>No of responses</b>	<b>%</b>
My GP	3	15%
Other health professional – as part of another health problem	1	5%
I noticed myself that I was having problems	14	70%
Somebody else (family/friends) noticed something was wrong	2	10%
Other (please give details)	0	0



<b>Question 3 – How easy was it for the person you care for to get a confirmed diagnosis of dementia?</b>	<b>No of responses</b>	<b>%</b>
It was very easy – professionals listened	15	75
It wasn't as easy as it should have been – I had to convince professionals that there was a problem	4	20
It was very difficult – professionals dismissed my early concerns, and did not listen	1	5

<b>Have you received enough information about dementia?</b>	<b>No of Responses</b>	<b>%</b>
Yes	17	85
No	3	15

**What other information would you like? Please describe:-**

- What are the long-term symptoms. How to go about choosing residential care. What costs will be incurred in residential care.
- Need more aftercare after diagnosis
- General information
- I find the website 'Talking Point' very good
- I have received information by researching it myself. I would like to have been signposted to support organisations
- Sometimes it seems too much

**Please give details of any problems you faced as a carer or things that went well:-**

- I found it difficult at times when I have been ill myself
- Getting reliable carers. So many just do it as a job and do not seem to remember that the patient is also a person. It was extremely hard coping with the patient's frustration.
- Main problem was distance. I was too far away so had to rely on Social Services
- Having considerable patience
- It is a very long road having to do everything that was done by two, especially making all decisions. Lack of help with transport
- No major problems as yet
- Acting as a memory bank
- Main problem is working my way through the minefield of financial support
- The initial memory test is not conclusive and the carer has a more accurate insight in the early stages. The initial diagnosis lacked empathy, understanding and any avenue of support. We were left reeling
- Meeting at Keystones (St. Lukes Church, Crosy) excellent help
- Getting a diagnosis for a 54 year old, then getting good care and getting appropriate support
- Being part of the Alzheimers society is a godsend
- Original diagnosis was vascular dementia - no medication. 6 months later, different doctor reviewed CT scan, etc., and re-assessed as mixed dementia and donepezil prescribed. 6 months with no treatment was wasted time/Opportunity??

<b>Question 4 -</b> <b>Here are some things that people with dementia have said are important to them. Are they important to you as a carer?</b>	<b><u>Yes</u></b>	<b><u>No</u></b>
In terms of healthcare I will be able to be seen by the same person and not have to repeat my story over and over again to different people.	17	0
The person I care for will always be asked what they want, even when they find it difficult to answer.	15	2
The person I care for will be able to communicate their likes and dislikes where ever they are living	14	3
The person I care for will have a say in their end of life plan and will be supported to die peacefully in a place of their choosing.	12	0

**The following comments were made in response to the above questions:-**

Being able to see the same person every time

- It is very helpful if the person with the dementia can be seen by the same person. They can't always speak for themselves because of their problems.
- Carer has to repeat general day to day. Particularly medical appointments and happenings.
- Yes - going to Alzheimers Groups very important
- Very important - doctors at memory clinic different every time you go. No continuity of care.

The Person I care for will be asked what they want

- Very important. You should try not to lose sight that the patient is a person
- Yes, sometimes they do understand just don't remember the decisions made
- Yes, but they need to be included.
- You always try to give them choice but most times they cannot decide for themselves
- Yes and ask me what I want.
- They must be treated as individuals for as long as possible with the carer's advice sought as back up
- Important. As disease progresses this is increasingly difficult to achieve. A lot of patience needed.

#### The person I care for will be able to communicate their likes and dislikes

- Should be able to. The system should be constant
- No one knows what the future will bring. I hope the person can stay at home for as long as possible.
- No - change upsetting
- Not always
- Less important. This is likely to be known by spouse, family

#### The Person I care for will have a say in their End of Life Plan

- Important but obviously should be discussed whilst the patient is still able to make decisions.

- Done early enough, yes.
- I hope they are able to choose, and that hospitals and care homes have the right training for staff.
- Have not considered this
- Not considered yet
- This needs to be addressed early on before it is too late due to advancement of disease

**Question 5 – Now we would like to ask you about the services that you receive to help you and the person you care for cope with dementia**

Did you have a choice of provider?	No of responses	%
Yes	4	22
No	14	78

**What do you think of the services they provide?**

- He has attended the Willows in Maghull when I had operations. They were very good with him.
- Poor standards
- We set up a care package but effectively it could never work because they were not able to be there 24/7
- Able to manage at home at this present time
- Excellent service from Sefton for Care and help in improving home environment
- Excellent

- At present none received or wanted but I know where to look for help if required
- I went to Alzheimer's society for information and support and their support staff and services are excellent
- I thought it was very poor and after research I realised I could request an out of area referral and did so. I also wrote to lots of people to highlight the inadequacies and received a social worker visit which was good
- Good
- Cared for by family at home only support by GP, memory clinic and community nurse. Needs to be better co-ordination and links between services. All very hit and miss. No one takes the lead. Responsibility not clear

<b>Question 6 – has the person you care for spent time in hospital?</b>	<b>No of responses</b>	<b>%</b>
Yes	4	22
No	14	78

**If you answered yes please tell us about your experience of hospital**

- They were ok but I noticed they just put the food down and left him to eat it. Luckily I took him homemade chicken soup every day so I knew he was eating a little.
- But not for dementia
- But not for dementia - an operation on her hand became infected and she spent 3 weeks in Whiston. Care was very good but the individual rooms were like prison cells with no view from the windows due to renovations on the exterior

<b>Question 7 – Do you have opportunities to meet and talk to other people with dementia and/or other carers for people with dementia?</b>	<b>No of responses</b>	<b>%</b>
Yes	13	68
No	6	32

**If you answered No what opportunities would you like?**

- At the moment I would like him to go to a Day Centre for one day a week for him to mix with different people.
- To be able to talk to carers in similar situations would be very useful. As ideas, methods used, etc., could be swapped
- Did have very good chats with the psychiatric nurse. Gave us some good advice which stood me in good stead.
- Have help from various groups
- One-to-one counselling. Not group social activities

**Question 9 – is there anything missing from these questions that is important to you (please tick all that apply)?**

- That all people can get the help they need without being financially assessed. It is very difficult on public transport to get to a care centre
- The circumstances of the initial diagnosis are very important and should be treated with understanding and compassion by professionals

Question 10 - Would you like the following people to have a better understanding of dementia?	No of responses
Family	13
Friends	10
Employers	4
Hospital Staff	10
Social Workers	4
GPs	8
Care Providers	4
People who work in shops, banks, offices and post offices	10
Police	7
Other:- <ul style="list-style-type: none"> <li>• Everyone</li> <li>• All people with whom we have had contact with have been very supportive</li> <li>• Transport</li> </ul>	





**Question 11 – details of any discussions you feel are important**



- Being able to come to the memory clinic to discuss any problems we may have
- Although there are a lot of people waiting to help and a lot of information that is available, it can be a bit of hit and miss on whether you get all the support you need. For example it took some time before I realised I could be registered as a carer and I didn't know until I asked, that you can purchase items for use by the person suffering from dementia VAT free. Perhaps when a person is first diagnosed with dementia somebody should identify



who the carer is going to be and make sure they have a copy of something like the excellent "Dementia Guide" published by the Alzheimer's society.

## About You

<b>What is the first part of your Post Code</b>		L22 1 7% L23 1 7% L30 2 14% L31 2 14% L37 2 14% PR8 1 7% PR9 5 37%
<b>Are you:</b>		Male 7 41% Female 10 59%
<b>What is your age?</b>		16-24 0 0% 25-39 0 0% 40-59 1 6% 60-75 11 61% 75+ 6 33%
<b>Disability – Do you have?</b>		Physical Impairment 0 Visual Impairment 4 Learning Disability 0 Hearing Impairment/ deaf 3 Mental health/ Mental Distress Long Term Illness 1 Other: Diabetes Osteoporosis
<b>Do you class yourself as disabled?</b>		Yes 1 7% No 13 93%

<b>Ethnicity</b>		White British      14      74% White English      3      16% White Welsh      1      5% Black English      1      5%
<b>Do you have a religion or belief</b>		Yes                  11      65% No                    6      35%  11 people identified as Christian

## Questionnaire for Carers who had recently lost a person with Dementia

A questionnaire was developed to help us to understand the experiences of people who had recently lost a person with dementia. This was also to determine whether end of life plans were in place and if so if they were followed.

The Sefton Carers Centre facilitated this small sample of returns – 3 people completed the questionnaires.

### Question 1 – How long did the person you are for have dementia?

- 3-4 years – Deceased 2013
- Official diagnosis 5/12 - Deceased 7/13 - Probable length of illness 2-3 years
- Approx 10 years

<b>Question 2 – where did the person you cared for pass away?</b>	<b>No of responses</b>	<b>%</b>
At home	0	0

In hospital	1	33
In a care home	2	67

<b>Question 3 – did the person you cared for have an end of life plan in place?</b>	<b>No of responses</b>	<b>%</b>
Yes	2	67
No	1	33

<b>Question 4 – were the wishes of the person you cared for as stated in the plan carried out?</b>	<b>No of responses</b>	<b>%</b>
Yes	2	100
No	0	0

**Question 5 – What support did the person you cared for receive in their final days and who from?**

- Care Home staff made mum comfortable and clean at all times
- NHS/Alzheimer’s Society support
- Support from family, care home staff, GP, mental health team, district nurses, priest

**Question 6 - What support did you receive and who from?**

No responses given

**Question 7 - Were you and the person you cared for treated with respect and compassion and kept informed as to what was happening?**

- Yes, once in the care home

**Question 8 - What did you feel was helpful to you and the person you cared for during the process?**

- The compassion shown by the care home

**Question 9 - What did you feel was not done well and made the process difficult for both you and the person you cared for?**

No responses given

**Question 10 - Is there anything you would like to add?**

Getting a diagnosis was very hard as letters from the GP were sent to mum. Also found out about Alzheimer's Society far too late. But that is now starting to change. Mum was not diagnosed with dementia until she was in hospital for another reason

DRAFT

## The Public Questionnaire

The questionnaire was available on-line (via e-Consult) and also as a hard copy. Distribution of hard copies was supported by the Sefton Pensioners Advocacy Service (SPAC), the Alzheimer's Society and the Sefton Carers Centre. It was available for people to complete from 28<sup>th</sup> May 2014 – 10<sup>th</sup> August 2014. A copy of the questionnaire is attached to the report.

The purpose of the questionnaire was to ascertain people's knowledge and perceptions of dementia in general, and to test out whether the aims and objectives in the Strategy were the right ones.

A total of 78 people completed the questionnaire. 70 people have fully completed the questionnaire and 8 people have partially completed the questionnaire (i.e. they have not answered one or more questions in the consultation; this may include monitoring questions).

It is important to note that these results are not representative of the Sefton population. The results of the questionnaire will support the feedback from the other engagement methods used.

<b>Question 1 – We would like to know about your level of understanding about dementia. Please answer true or false to each of the following statements</b>	<b>No of responses True</b>	<b>No of responses False</b>
Dementia is a disease of the brain <b>(True)</b>	73	2
Dementia can be cured <b>(False)</b>	70	4
There are drug treatments that help with dementia <b>(True)</b>	66	5
There are many different kinds of dementia <b>(True)</b>	68	4
Dementia is part of the normal process of ageing <b>(False)</b>	9	64
People who eat healthily and exercise are less likely to get dementia <b>(True)</b>	28	43
Most people with dementia live in care <b>(False)</b>	8	66

<b>Question 2 – If somebody has been diagnosed with dementia do you think that they should:-</b>	<b>Agree</b>	<b>Disagree</b>	<b>Not sure</b>
Continue to live alone	21 (31%)	27 (38%)	27 (38%)
Be supported so that they can continue to work as long as they can	70 (93%)	3 (4%)	2 (3%)
Continue to drive as long as they are able	51 (69%)	13 (18%)	10 (13%)
Use technology to enable people to stay safe in their home	65 (88%)	1 (1%)	8 (11%)
Have a single point of contact for their dementia care	65 (89%)	0 (0%)	8 (11%)

<b>Question 3 – These are some statements that have been made about people with dementia. Please indicate whether you agree, disagree or are not sure about each:-</b>	<b>Agree</b>	<b>Disagree</b>	<b>Not sure</b>
People with dementia should be involved in activities in the community	72 (98%)	1 (1%)	1 (1%)
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home.	4 (5%)	53 (72%)	17 (23%)
There is little or no benefit to be gained from telling someone they have dementia	15 (21%)	36 (49%)	22 (30%)
People who have just been diagnosed with dementia are unable to make decisions about their own care	6 (8%)	63 (86%)	4 (6%)
There is no point in trying to talk to people with dementia as they won't be able to understand	1 (1%)	66 (92%)	5 (7%)

**Do you have any comments about any of these statements?**

- This will be dependent on severity and how far the dementia has progressed and how long they had dementia before they were diagnosed.
- I think that people with dementia should be involved - included in as many activities as their illness allows. I also think that you should continue talking as they can be reached by part or parts of the conversation.

- See question above about being cared for in residential unit or care home - depends on the stage of their dementia. Later stage advanced dementia is better cared for in a residential unit where specialist care is available.
- My opinion currently through the experience of looking after my mum who had Alzheimer's Dementia is that there is no point in getting a dementia diagnosis. There is very little support, you are on your own. GP's, Memory Clinics and NHS are all poor for understanding and support. They just do what they have got to do to tick the box, get the QUOF points and stuff like that.
- Though there can be confusion it is my experience that there is much understanding and less fear if they can do as many of the normal things as possible.
- I think a lot of the statements above are considerations that need to be thought about depending on each individual circumstance. The dementia consultant told my dad that there wasn't much point trying to explain to mum that she has dementia as she wouldn't remember BUT my mum does remember some things and I think it is important to try and help her understand.
- All cases are as individual as the person is. It also depends on family and support of family. No one knows what its like to live with this debilitating illness. Carers need more help in every aspect and different levels of dementia need different support. Activities, exercise and respite is very important to both carer and the person with the condition. This is not always possible because of all the obstacles and no one understanding. Training of staff of establishments to which we could attend. Carers' allowance should be looked at too - and the limitations to obtaining this should be lifted.
- It is not practicable to give a simple answer to the statements as more information about the individual involved and more clarity about the actual situation is needed (What does '... just been diagnosed ...' mean? The person could be at the early stages or the later stages when they have just been diagnosed) essentially, each individual is different and needs to be treated differently although some aspects may be common to many cases.



- Most of these answers would depend on the stage of dementia. People with early onset dementia would understand diagnosis and carry on making their own decisions.
- These statements imply that dementia is a fixed condition with "one solution fits all". It is a complex and multi-faceted disease with most patients experiencing differing levels of capacity and understanding at different points in the disease.
- I don't know anybody with dementia
- I really don't know enough about dementia to offer an opinion
- People with dementia are human beings and should be treated as such
- Need more intervention as disease progresses
- You can't give up on people with dementia. They need mental stimulation and everyone is an individual.
- People who are diagnosed with dementia and live at home should, with help from family if possible. They should be given the choice until such time as their dementia is in need of extra care.
- Apart from the first statement, all the others are very negative.
- Questions 1+2+4+5 answers would depend on the progress of the dementia in the individual. I have presumed that the person is in the early stages rather than the later stages.
- Yes - the person with dementia is me and it is at this point loss of memory As a registered person with some loss of memory I still live on my own, do absolutely everything on my own in the home and outside (even though I probably do things twice over!, lose things, forget things). Up until now I have not missed any doctor's appointments, missed a bus or train, but I do have to write everything down in several places around the house. It is pleasant when I can spend a few days here and there with members of the family - shelve some of my responsibilities. My writing has

deteriorated badly but I still write quite a lot of letters. I attend 6 or 12 months assessment of abilities, and have done so for three years.

- Depends on the severity and advancement of the dementia
- Not sure about some answers. Depends how far into dementia they are. Some I know are in early stages and understand. Short term memory that's all, remember everything years ago.
- The last four statements epitomise many people's (who do not know exactly what dementia is and how it can develop) opinions
- A lot depends on the severity of the dementia
- Very thorough and thought provoking
- I really do not know enough about dementia to give an opinion
- It all depends on the level of dementia. At first it is quite manageable but it is important to be able to identify the stage when they can no longer carry on their normal activities
- If people who have dementia are fortunate enough to have someone to love and care for them as long as it is possible, they are the lucky ones. the ones with no-one then must be placed in safe care.
- Must listen to people with dementia and their families, need to be involved in decision making they are the experts in what is happening individually to them.
- People with dementia should continue to live well in their community. Advice & support should be accessible. Early diagnosis so they can plan for the future and receive medication if suitable.
- There is a need for education and increased awareness around the condition to ensure everyone has a greater understanding of the conditions and how people can be supported.

- I think many of the above questions above don't give a true value as to how progressive Dementia is and at what stage intervention is required.

<b>Question 4 – The Government launched the Prime Minister’s Dementia Challenge in 2012. This includes creating dementia friendly communities. What do you think dementia friendly communities look like</b>	<b>Agree</b>	<b>Disagree</b>	<b>Not sure</b>
People with dementia are supported to remain active and included members of their communities	72 (95%)	0 (0)	4 (5%)
People will have increased understanding and awareness about dementia and how to support individuals with dementia.	71 (93%)	1 (1%)	4 (5%)
To support individuals living with dementia and their carers to maintain their independence for as long as possible	73 (100%)	0	0
People with dementia being treated as valued members of society	67 (88%)	0	9 (12%)
People with dementia and their carers feel comfortable in their local environment (shops, leisure facilities, etc.)	68 (91%)	0 (0%)	7 (9%)

	<b>Agree</b>	<b>Disagree</b>	<b>Not sure</b>
People who work in the local community are trained to respond to the needs of people with dementia and do very simple and	70 (93%)	0 (0%)	5 (7%)

practical things that can make an enormous difference			
Implementing simple steps to help people with dementia such as slow lanes in supermarkets and banks	47 (64%)	11 (15%)	15 (21%)
Support from befriending groups to help people with dementia do the things that they want to	71 (99%)	1 (1%)	0 (0%)

### Any other comments?

- Not so sure about the "SLOW" Lane in supermarkets/banks. This is secluding people with dementia. I recently became a dementia friend and found it very rewarding. Society needs to become more sympathetic and tolerant towards people with dementia.
- We just want understanding, trust, patience but to be treated normally with respect and to feel comfortable.
- Awareness of dementia is improving which is very good.
- I agree with all the above points but to achieve the above would be amazing.
- I have never attended any such groups - never been offered - but I don't think I could. Nice to sit down in the evening to watch a programme or two on TV. For me its a strain to have to answer questions when I am assessed.
- The last but one statement only applies to more advanced stages of dementia. Where possible they would not be made to feel to be a burden on society
- Slow lanes might make other users irritated and the sufferer feel loss of dignity.
- Again, some things will only be a real handicap when dementia is advanced. It seems a bit presumptuous to provide slow lanes. Perhaps these would be useful if dementia is advanced. It seems a bit patronising (is that the word I am searching for?)

- When is all this going to happen?
- Families should not have to fight constantly for support from social services
- Peer support for both carer and person with dementia. Access to advice, one on one support.
- I think day-centres may be best suited to accommodate Dementia suffers as they will be able to stimulate individual minds and monitor progress. Also provide less stress for working family members, knowing their loved one is safe.

**Question 5 - The following questions relate to your thoughts about the Dementia Strategy and the Strategic Objectives for 2014 - 2019**

**Aims for People with Dementia**

These are the aims included in the draft strategy which will help people with dementia and their carers live their lives in a positive way. Please rank them in order of importance where 1 is the most important and 9 is the least important.

These are the results of the surveys with the aim getting the most number of 1 ranked first, etc.

Rank

1. People with dementia should be diagnosed in a timely way
2. People with dementia are treated with dignity and respect
3. People with dementia get the treatment and support which is best for their dementia and their life
4. People with dementia will have help in planning for their future health and care needs through a co-ordinated health and social care service.
5. People with dementia's wishes with regard to end of life will be respected

6. People with dementia know what to do to help themselves and who else they can go to for help
7. Those looking after people with dementia are well supported.
8. People with dementia should feel included as part of society
9. People with dementia can make decisions for themselves

### **Strategic objectives for people with dementia in Sefton**

These are the Strategic Objectives in the draft Strategy that will provide people with dementia and their carers with the support to live their lives in the way they would want to? Please rank them in order of importance where 1 is the most important and 5 is the least important :-

These are the results of the surveys with the aim getting the most number of 1s ranked first, etc.

#### Rank

1. Timely diagnosis, appropriate treatment and involvement in care plans
2. Support to live independently for as long as possible, and to make decisions for myself
3. Inclusive and dementia friendly communities
4. Information, advice and support for people with dementia and their carers
5. End of Life Services, ensuring a peaceful and pain free death in the place of choice.

### **Question 8 – Do you have any other comments about the Strategy or have we missed something?**

The following responses were given:-

- I think all the above are very important and should be included in a comprehensive holistic approach.

- The strategic vision sounds good on paper but how are these objectives going to be implemented and met in practice. I feel the support for my mum who was diagnosed before Christmas has been really poor. I don't feel like we know where to go for support. The memory clinic we attend with mum says there are things like day centres my mum could go to but then we hear no more information and don't know where to go. The Social Care is supposed to be coming round to assess mum in her home - we are still waiting. It is all these things that on paper the strategic plan sounds good but not sure where the support is or how we access it.
- All these questions are for early onset. Every GP should have the ability to give all the patients on their books a well check alert after they are 60 and then every 5 years after that. This would make sure that a lot of people with early signs of dementia do not slip through the net and get the help and support they need. Financial help without means testing i.e. carers' allowance should be available to all even those on pensions as they are still carers no matter what age you are. Recognise dementia as a terminal illness.
- End of life services should not distinguish people with dementia from other people in similar situations. The implication of the above appears to be different from what is now legally available for all people.

- I would have liked the option to put many of these options as joint priorities especially for younger dementia patients which is what I am familiar with. Younger dementia patients need access to early diagnosis screening as it is so often misdiagnosed as anxiety or depression and specialist advice and support as risk management is harder for more mobile patients whose carer may still be employed and supporting children.
- I found ranking the aims difficult. I feel that the vast majority are ranked 1 because they are all interconnected. Early diagnosis is KEY. Support for independent living is vitally important. Information, advice and support are crucial keys. I am anxious when I see "End of Life" approaches. I would love 'Hospice Care' for all but am uncertain about offering medical professionals power to influence or provide 'end of life' services. 'The Liverpool Way' was a terrible thing though it meant well.
- Troubled by end of life services. How do people with severe dementia make end of life choices? The Liverpool Pathway was flawed. I asked was this used in care homes. Still waiting for reply. Finances - a trusted organisation to look after dementia sufferers' finances. Is social isolation the right way? I think not. The strategy should also include carers. How many people are caring for loved ones who are not registered because of the stigma? A strategy for dementia should have been well in place.
- End of Life should be extended to give support to carers at this difficult time.
- Too many questions are repeated?? was this intentional?
- I can't answer these because we are all different, our needs are different. I do not have a carer but on occasions my daughter may give me a hand when I get particularly anxious. Hearing As an individual I am usually ignored in conversations, chiefly because I am slow to answer and have to ask for things to be repeated, having great difficulty in understanding a lot of words. I use two hearing aids which still lack clarity. Loop system is used very little and those that have it don't understand how it works. I once asked a Post Office assistant to switch on the loop system After searching underneath the counter for ages she came up with a








very dirty looking piece of equipment but didn't manage to get it working - so we struggled on!





- They are all important. End of life services!!!?? I have sat with a friend where the family had agreed to the Pathway, where food and water is withdrawn, only they didn't sit with her and I never want to again, she was begging for a drink of water, tea, anything she said. I feel it's open to abuse. It made me ill. I couldn't get her out of my mind day or night. I'm sure the hospital didn't manage it properly. I did phone up and complain without the family knowing and said I think they had a few Dr. Shipmans working there, one nurse was horrible.
- Very difficult to rate any of these questions as they are all very important in their own way
- What does diagnosed in a timely way mean? Does it mean early? If people have dementia how do they know what to do? People with dementia should be part of society as long as they are aware yes
- I am so pleased that the strategy takes on board the knowledge that many people reaching the end of life want some control over their death. We all will die some day but why should we suffer the pain, the indignities and the fear of a horrible death. It is barbaric and in this day and age should be totally avoided. We put animals down for less than some people have to suffer. We should be given a form from our doctors as a matter of fact so that we can make a decision whilst we are of sound mind so that the doctor is aware, well ahead of end of life, that that is our dearest wish if that be so.
- I don't think ranking is helpful as it implies that items ranked lowest are not important which is not the case - all these aims are important
- Quicker response for support and care from staff specially trained and skilled at listening and communicating
- Advocacy

- It was difficult to rank the Q1 and Q2 statements as there were no least important ones
- Care staff should receive full training, experience and be able to cope and assist with changes to the individual as their prognosis develops. Also it is important nutritional care is given to maintain a healthy body and mind.

### Equalities Monitoring

Post Code 	Completed by 53 people	<table border="0"> <tr> <td><b>CH45</b></td> <td>1</td> <td><b>L20</b></td> <td>2</td> </tr> <tr> <td><b>L21</b></td> <td>4</td> <td><b>L22</b></td> <td>1</td> </tr> <tr> <td><b>L23</b></td> <td>3</td> <td><b>L30</b></td> <td>2</td> </tr> <tr> <td><b>L31</b></td> <td>12</td> <td><b>L37</b></td> <td>2</td> </tr> <tr> <td><b>L38</b></td> <td>2</td> <td><b>L39</b></td> <td>1</td> </tr> <tr> <td><b>L40</b></td> <td>1</td> <td><b>PR8</b></td> <td>13</td> </tr> <tr> <td><b>PR9</b></td> <td>9</td> <td></td> <td></td> </tr> </table>	<b>CH45</b>	1	<b>L20</b>	2	<b>L21</b>	4	<b>L22</b>	1	<b>L23</b>	3	<b>L30</b>	2	<b>L31</b>	12	<b>L37</b>	2	<b>L38</b>	2	<b>L39</b>	1	<b>L40</b>	1	<b>PR8</b>	13	<b>PR9</b>	9		
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Disability 	<p>People indicated that they have a disability as follows:-</p> <p>37 people consider themselves disabled</p>	<table border="0"> <tr> <td>8</td> <td>Have a physical impairment</td> </tr> <tr> <td>5</td> <td>Have a visual impairment</td> </tr> <tr> <td>0</td> <td>Have a learning difficulty</td> </tr> <tr> <td>10</td> <td>Have hearing impairment</td> </tr> <tr> <td>3</td> <td>Have mental health / mental distress</td> </tr> <tr> <td>13</td> <td>Have a long term illness</td> </tr> </table>	8	Have a physical impairment	5	Have a visual impairment	0	Have a learning difficulty	10	Have hearing impairment	3	Have mental health / mental distress	13	Have a long term illness																
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Ethnicity 	Completed by 65 people	<table border="0"> <tr> <td>White British</td> <td>38</td> <td>57%</td> </tr> <tr> <td>White English</td> <td>26</td> <td>40%</td> </tr> </table>	White British	38	57%	White English	26	40%
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White English	26	40%						

		White Welsh 1 1% Black British 1 1% Indian 1 1%
Religion	 Have a religion completed by 59 people	Have a Religion 45 76% 42 (71%) are Christian
Sexual Orientation	 Completed by 65 people	Heterosexual 54 83% Gay 2 7%
Gender	  Completed by 60 people	60 (100%) Live in the gender assigned at birth

## What will happen with what you have told us?

We will take on board what people have told us and make sure that it is reflected in the draft Strategy for Sefton. The Strategy will be approved by the Cabinet Member for Older People and Health and will form part of the Sefton Health and Wellbeing Strategy.

An Action Plan will be developed for the Strategy and progress against actions will be monitored.

The Strategy is a living document and will be refreshed and updated as legislation and guidance is updated. The Strategy and action plan will be published on the Council's website.

# Contributors

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## List of Contributors to Living Well with Dementia: A Strategy for Sefton 2014-2019

### (No particular order)

This list contains the people and organisations that offered sustained and invaluable support to the process. We would like to thank everyone who was part of the process and it would be impossible to list and thank everyone as it was a huge piece of work. In particular we would like to thank:

- Councillor Paul Cummins, Cabinet Member for Older People and Health
- NHS South Sefton CCG
- NHS Southport and Formby CCG
- Sefton CVS, Mersey Care NHS Trust
- Alzheimer's Society
- Sefton Pensioners Advocacy Centre
- Age Concern
- Sefton Partnership for Older Citizens
- One Vision Housing, Care Homes Association
- Liverpool Community Health NHS Trust
- Southport & Ormskirk Hospital NHS Trust.
- Sefton Council Business Intelligence and Performance Team

**Finally we would like to acknowledge and thank all the people of Sefton who contributed to this report.**

# List of Organisations who took part in the Open Space Innovation Events

Sefton Carers Centre  
Southport District General Hospital  
Community Emergency Response Team (Southport Hospital)  
Parkhaven Trust  
Living Well Centre, Southport  
Sefton CVS  
Care Connect  
Sefton Council Public Health  
The Alzheimer's Society  
Sefton Council Adult Services  
Community Integrated Care (Green Heys)  
Lifestory Network  
Merseycare  
One Vision Housing  
Councillor Pat Keith  
Councillor Sue McGuire  
Birch Abbey  
ICCM  
The Footcare Service  
The Regenda Group  
Sefton Pensioners Advocacy Service  
Ainsdale Community Centre  
Vitalise - Sandpipers  
Brookdale Resource Centre  
Brighter Living Partnership  
Councillor David Barton  
Sefton Community Learning Disability Team  
Memory Clinic, Merseycare NHS Trust