

healthwatch

Middlesbrough



Making Middlesbrough more dementia friendly

Toni McHale

July 2015

Contents

| | |
|---|-----------|
| 1. Background | 3 |
| 1.1 What is Healthwatch? | 3 |
| 2. Aim of the Report | 3 |
| 2.1 Background and Rationale | 3 |
| 3. Methodology | 5 |
| 3.1 Acknowledgments..... | 5 |
| 4. Findings | 5 |
| 4.1. Survey Results | 5 |
| 4.2 Engagement Findings..... | 7 |
| 5. Summary | 13 |
| 6. Recommendations | 13 |
| 7. Appendices | 15 |
| 7.1 Full Survey Results | 15 |
| 7.2 Dementia Friendly Community Public Event Findings | 24 |
| 8. References | 32 |

1. Background

1.1 What is Healthwatch?

Healthwatch Middlesbrough is a patient and service user voice organisation. We listen to people's experiences and views of local health and social care services. We use this information to help influence how services are planned and delivered in the future to make sure they meet the needs of those people using them.

We gather the views and experiences of people in a number of different ways including but not exclusive to face to face engagement, online surveys, Facebook and Twitter and by attending local events and focus groups.

Healthwatch Middlesbrough is an independent organisation steered by a Board of volunteers. Healthwatch is commissioned by the Local Authority and accountable to the public.



Healthwatch has statutory powers:

- A statutory seat on the Health and Wellbeing Board
- The statutory right to be listened to. Providers and commissioners must respond to us within 20 days of submissions of requests for information or reports
 - The statutory power to Enter & View health and social care services

Our aim is to strengthen the collective voice of local people and to enable them to find the right health and social care services for them by providing appropriate information, advice and signposting.

2. Aim of the Report

2.1. Background and Rationale

In England, it is estimated that 676,000 people have dementia ^[1]. It is expected that this figure will double in the next 30 years as life expectancy increases. The Government has stated that it has made significant progress since 2010, by doubling investment in research, recruiting 1 million “Dementia Friends” and giving specialist training to NHS staff.

In the Department of Health (2012) Prime Minister's Challenge on Dementia: (Delivering major improvements in dementia care and research by 2015. Department of Health: London) the Prime Minister said:

“Dementia is one of the biggest challenges we face today - and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go. One of the main three aims was to create dementia friendly communities that understand how to help - including improving awareness among the public; and the establishment of recognised dementia-friendly communities, led by the Alzheimer's Society. Over 50 communities across England have signed up to the national Dementia Friendly Communities recognition process.” [1]

The North East Charter for Changing Age [2], adopted and endorsed by all the Local Authorities in the North East is a call to action to respond positively to the challenges and opportunities presented by an ageing population. The fundamental principles of the North East Charter on Changing Age are undoubtedly relevant to Middlesbrough becoming more dementia friendly.

Healthwatch Middlesbrough is pleased to present the findings from our consultation. The report considers the need for a dementia friendly community, describes the current services available in the town, and makes recommendations for the future changes.

During consultation the people of Middlesbrough told us that they wanted Middlesbrough to be more dementia friendly. In endeavouring to make Middlesbrough more dementia friendly it is imperative that the views and opinions of people living with dementia and their family, friends and carers are at the heart of any considerations or decisions.

Why was it important to ask the people of Middlesbrough what their priorities are, including those living with dementia?

- People with dementia have a right to a say in decisions that affect their lives.
- Involving people with dementia sends an important message about the values inherent in the notion of dementia-friendly communities.
- It engenders a sense of ownership and investment.
- On a practical level it gives us somewhere to start in developing dementia friendly communities. If people with dementia tell us they all want to use the shopping mall - then we begin with the shopping mall.

The most important stakeholders in this process of course are people with dementia, those who care for and support them and the residents of Middlesbrough.

3. Methodology

Healthwatch used several methods to collect intelligence from people who live, work or care for someone in Middlesbrough to ensure a good overview was collected. We wanted to capture what was important to the public in making their town more dementia friendly. We did this via:

- A general survey which was conducted over the period of December 2014 to April 2015.
- A Survey Monkey questionnaire which was distributed via our Website, Facebook and Twitter.

In addition targeted focus groups were held with the following community groups:

- Life Store Middlesbrough Dementia Support Group
- Sanctuary Supported Living Dementia Pub Lunches
- Sanctuary Supported Living Dementia Adviser Service

A public event was held in June. The event was attended by over 50 people including those from local businesses, transport and support groups. It should be noted that the focus groups made the decision to concentrate on the surveys therefore no additional notes have been included from these sessions.

3.1 Acknowledgments

Healthwatch Middlesbrough would like to thank everybody who took time out of their day to complete our survey. In addition we would like to thank Sanctuary Supported Living Dementia Adviser Service and the Life Store Middlesbrough for their support.

We would also like to thank the Dementia Action Alliance - North East and Alzheimer's Society - Durham and Tees Valley Locality for their support in the public event.

We also acknowledge the North East Dementia Alliance and the author, Peter Prior, for the information accessed via the Foundations of dementia friendly communities for the North East Perspective Report ^[3].

4. Findings

4.1 Survey Results

It should be noted that the survey was a snap shot in time and not meant to be a scientific study. The most common themes are highlighted below. A record of all responses can be found in the appendices 7.1.

59 people completed the survey. Of those 59 people:

- 13 were living with dementia or had memory concerns
- 23 were carers of friends of people with dementia
- 5 worked with people with dementia
- 24 were general members of the public

You will see from the figures some people felt that they fit into more than one category.

Those who completed the survey came from a good mix of Middlesbrough wards and also included 5 from out of area. This would be expected as some carers may live in the area and care for someone with dementia from out of area or vice versa.

When asked, *“When you are out in your local area what sort of things do you do?”* The most popular answers were:

- Shopping
- Paying bills such as rent
- Walking
- Visiting cafes
- Visiting friends

We then asked, *“Is there anything that helps you to do the things in Middlesbrough you enjoy?”*

The key things that helped were:

- Plenty of good seating available both inside and outside of shops
- Good lighting
- Clear signs
- Having someone with me(carer)
- People being aware of dementia and how it affects a person

When asked, *“Is there anything that makes it more difficult for you to do the things you enjoy?”*

The main points were:

- Lack of understanding about dementia from the general public
- Lack of understanding about dementia from shop workers and those working on public transport
- Uneven flooring
- Lack of seating and clear signs in shops

When asked, *“Why have you have stopped doing things you used to enjoy?”* the response was:

- Reliance on public transport and the cost
- Do not know what is available

- Cost of swimming etc.
- People's attitudes

When asked, *"Is there anything which may help you start doing the things you liked but no longer do?"*

- More awareness from shop keepers. Perhaps all shops should have a dementia lead a little like they have a first aider
- More awareness around dementia and a person's needs on public transport
- Better lighting and exit signs in shops
- More seats inside shops

Finally we asked, *"What do you think could be done to make Middlesbrough more dementia friendly?"*

- Be more open about dementia
- More training and awareness
- Listen to and support those caring for someone living with dementia
- Dementia cafes
- More staff awareness in nursing homes and hospitals

A comment box was added to provide people with the opportunity to contribute anecdotal evidence. A point highlighted throughout our consultation was that dementia is only one part of a person they still have other needs such as attending GP, dentist, leisure, shopping, transport and socialising. Therefore when making Middlesbrough more dementia friendly all of these areas need taking into consideration.

4.2 Engagement Findings from Dementia Friendly Community Public Event

The event was attended by over 50 people with a mix of:

- General public
- Those caring for someone with dementia or memory concerns
- Those living with dementia or memory concerns
- Local police
- Local and national business
- Safe Scheme members
- Representatives from statutory and voluntary sectors.

Two of the key players in helping Middlesbrough become more dementia friendly were in attendance:

- Cleveland Alzheimers Residential Centre (Cleavearc) who are commissioned to help Make Middlesbrough Dementia Friendly.
- The Dementia Action Alliance - North East who are working with organisations to radically improve the lives of people living with dementia and their carers.

Healthwatch Middlesbrough have agreed to share all findings from our engagement with both organisations to help launch their work and avoid unnecessary duplication. This sharing of intelligence will ensure that people are not asked the same questions again and that information gathered can be used to help the people of Middlesbrough. Both organisations have agreed to acknowledge Healthwatch Middlesbrough for their input into their work.

The morning began with an outline of why the event was being held along with an overview of what makes a town more dementia friendly. Importantly it was stressed that the information gathered would be used to shape recommendations which would be passed to the commissioners of services to ensure future services better meets the needs of the people in Middlesbrough.

Past evaluation has shown Healthwatch that people are not comfortable in talking in large groups and therefore their valued comments and experiences can be lost. To ensure as many people present had their voice heard we split into 6 groups. Each table had a facilitator and a scribe. The exercise was to discuss:-

When I am out and about in Middlesbrough

- The things that make it easier/better and why?
- The things that I struggle with or make it more difficult to be out and about and why?
- Using the information gathered which changes would make the most difference to you.

We stressed that all of the changes highlighted in the first part of the discussion were important, because of the importance to the person who raised them. However, as it would be impossible to implement all of the changes at the same time (if at all) we asked people to take a few moments to prioritise the proposed changes collected on each table. It was acknowledged that whilst everyone on the table may not have agreed to each of the proposals; between them we asked that all of the suggestions and comments were placed on the line of importance. Ten being the most important zero the least. We took the top three from each table.

The priorities from each table were added to intelligence gathered from other sources to help form our recommendations in this report. The information will be shared with Action Alliance and the new Dementia Friendly Community work team funded by the CCG.

All of the findings were collated and can be found in the appendices 7.2.

The top three priorities from the 6 groups are:-

| | Top priority | Second priority | Third priority |
|---------|--|--|---|
| Table1 | Enable a person to live well with dementia for as long as possible | Educating people from young age so that they are more open to how dementia affects people and changes needed for Dementia Friendly communities | Raising awareness of dementia and how it affects a person |
| Table 2 | Need to train more people especially those who are in public services around what dementia is, the way it affects the person and the people who care for them. Also what can be done to improve things | Publicise Dementia Friends Champions and train more people | Make sure Safe Places are publicised and easily identified. Add to the number of venues signed up to the scheme to ensure improved networks |
| Table 3 | Emergency support needed for example "someone to contact when help is needed when I am out in the community if the person with dementia refuses to leave a shop or walks off" | Dementia friends training to people in the heart of the community so they can offer support and information locally | Spread awareness of dementia to Local Authority staff, shop workers, transport workers, café workers etc. |
| Table 4 | Staff training - more than what dementia is but how it affects | Maps available around the town of town where services are that | Radar key awareness and where accessible |

| | | | |
|---------|--|--|--|
| | people and how they can support them better | are dementia friendly. Also put on the map where key places are with easily identifiable land marks | toilets are available |
| Table 5 | Build dementia training into quality standards in customer service etc. A bit like all shops having a first aider | Discreet information card to use in shops etc. “I am living with dementia I may need a little more time or support” | When people and organisations sign up to do something make sure a mechanism is in place to evaluate and make sure it is making a difference and is still relevant to the people it is set. Things move on but services don't always move with them |
| Table 6 | More help at home as people with dementia can be vulnerable to callers (financial exploitation) | Carers need more support as we often cannot leave the people we care for at home alone so we become isolated | People with dementia are vulnerable when out and about in the community alone |

Summary of the main priorities for those present at the event:

- Raising awareness of dementia. To increase training for people from all ages, across all sectors and to encourage more people to be dementia champions
People felt they would be more comfortable using transport, visiting shops, cafes etc. if the people serving them had a better awareness of dementia and how it affected the person and their families

- Creating ‘Safe’ environments i.e. more Safe Places. It was felt that this scheme should be promoted much more widely and include ‘maps’ of where these services are and who to contact in an emergency
- Training and publicising of dementia friends
- The need for good quality, easily accessible timely information on what services were available to support a person with dementia
- Carer support

To round up the day we asked those present to make a pledge to help make Middlesbrough more dementia friendly. The following pledges were made:-

| Organisation | Pledge | Comments |
|--|--|--|
| Middlesbrough and Stockton MIND Ageing Better | To link in with all the work relating to this agenda as Ageing Better develops. To make sure Ageing Better Projects are dementia friendly and have good links with and understanding of how to support people with dementia and their carers | |
| The Trinity Centre, Heather Black | Work with churches to help them become more dementia friendly | Good to meet with lots of other people to talk about dementia |
| The Life Store | To provide a training room free of charge to businesses in Middlesbrough to train staff in becoming dementia friends | |
| Marks and Spencer | To get message to new members of staff. To make staff aware we are part of the Safe Place Scheme and remain Dementia Friendly | |
| Social Work student | | I am currently studying a social work degree at Teesside University just going into my final 3rd year. Learning to understand dementia |

| | | |
|-------------------------------|--|---|
| | | and their family's needs are very important to me. Also raising awareness I feel very passionate about it |
| Age UK Teesside | To ensure that all services provided by Age UK Teesside are accessible and dementia friendly for those living with dementia and their carers. This includes making changes to our work/activity room environments to ensure these are dementia friendly including improved signage and colour contrast | |
| Carers Together | Work collaboratively with Middlesbrough to make South Tees more dementia friendly. Support the development of DF Middlesbrough | |
| Name not provided | I will help raise awareness by delivering dementia friends sessions | |
| Name not provided | To link in with local dementia activity services and carers groups to offer know your own blood pressure info and advice. To signpost to Alzheimer's Society | |
| Middlesbrough Central Library | To extend dementia cafes to all libraries To become a dementia champion To promote Books on Prescription library service to all Middlesbrough GP's | |

| | | |
|-------------------|---|--|
| Name not provided | Work with the Safe Places Scheme to develop and promote the scheme further (MBC and Press Office) | |
|-------------------|---|--|

5. Summary

Middlesbrough has a vast amount of quality services and people who are ready to help make the town more dementia friendly. The general consensus of opinion from the small sample of people we worked with was that people were ready to commit to help to make the changes necessary. The areas for improvement could be split into 3 categories:-

Awareness and training - It came across very clearly that the people we spoke to did not think organisations and people in general knew enough about dementia and how it affected the person living with dementia and their families. This was especially true when they were accessing transport, shopping, cafes and leisure.

Environment - When out and about people struggled with the lack of clear signs (e.g. exit, pay here), poor lighting, lack of seats (especially in shops) and accessible toilets. Very few people had any knowledge of the Safe Place Scheme and how this could assist them.

Carers - Carers felt they could be better supported if the person they care for could go out alone or if they could have more support in the home to allow the carer to go out. Carers stated that more dementia cafes would be beneficial along with carer education around things that would make outings go more smoothly such as RADAR keys.

6. Recommendations

The information supplied should be used to help inform commissioners of services and local communities. The recommendations made by Healthwatch Middlesbrough are formed by the voice of those who engaged in this study and not those of staff members. In making the following recommendations Healthwatch Middlesbrough have considered what do we want to achieve by making Middlesbrough more dementia friendly and what changes do we need to make to achieve this. It would be normal for us to make our recommendations to one particular commissioner however, dementia affects the whole of the person and the responsibility for commissioning the following recommendations does not fall at one door. We therefore recommend a joined up response via Public Health

Middlesbrough, Middlesbrough Borough Council and NHS South Tees Clinical Commissioning Group (CCG). Individual commissioning bodies may feel that this will be best achieved by submitting this report to the South Tees Dementia Steering Group.

1. All findings be handed over to Cleveland Alzheimers Residential Centre (Cleavearc) and The Dementia Action Alliance - North East to assist in accelerating their ground work. Healthwatch Middlesbrough do ask that they are acknowledged by both parties for their input.
2. Middlesbrough Borough Council and Public Health Middlesbrough work together to target shops, cafes and transport staff to ensure they are more dementia aware. Possibly via dementia friend training. We would recommend this is done in conjunction with Cleavearc who have been commissioned by STCCG to help make Middlesbrough more dementia friendly and The Dementia Action Alliance - North East who are planning to work together with local organisations from public, private and charity sectors. The Alliance will be working with all sectors such as the emergency services, retailers and transport operators and community facilities to encourage local communities in Middlesbrough to become dementia friendly. This will be at the aim of increasing awareness of the condition and how the community can work together to reduce stigma allowing people with dementia to contribute as fully as possible to community life.
3. Middlesbrough Borough Council to extend and promote the Safe Place Scheme.
4. Middlesbrough Borough Council lead the way with their own buildings and work with local business to encourage improvements in lighting, seating and signage. The Checklists for dementia-friendly environments report suggest that the most important factors to be considered when designing internal environments appropriate for individual's living with dementia are the signage, lighting, flooring, seating and navigability. This is further endorsed in knowing the foundations of dementia friendly communities for the North East Report (2012) written by Peter Otter on behalf of North East dementia Alliance.

7. Appendices

7.1 Full Survey Results

1. About you, tick all that apply:

Please note even if you tick none of the above your views are still important to us. Most people have experienced the problems people with dementia face when they are out and have valuable suggestions of how things can be improved.

| | Number of people | % |
|---|------------------|--------|
| I am a person with dementia or memory problems | 13 | 22.03% |
| I am the carer or friend of a person with dementia or memory problems and I am filling this form on their behalf | 15 | 25.42% |
| I am the carer or friend of a person with dementia or memory problems and I am filling this form on my own behalf | 8 | 13.56% |
| I work with people with dementia or memory problems and am filling this form on their behalf | 5 | 8.47% |
| None of the above-Please note even if you tick none of the above your views are still important to us. Most people have experienced the problems people with dementia face when they are out and have valuable suggestions of how things can be improved. | 24 | 40.68% |

2. What area of Middlesbrough do you live or work? Please enter postcode.

| TS1 | TS2 | TS3 | TS4 | TS5 | TS6 | TS7 | TS8 | Out of area |
|-----|-----|-----|-----|-----|-----|-----|-----|-------------|
| 5 | 2 | 7 | 2 | 16 | 3 | 9 | 4 | 5 |

3. When you are out in your local area what sort of things do you do? For example shopping, visiting the library, or café, paying your rent etc.

Just visit family once 2 months
 Shopping, library, paying rent, collect both pensions, arrange medical appointments
 Mostly of the shopping and pay rent
 Shop, café, walking, visit rugby club, history club
 Shopping, call for a coffee
 Shopping, meal out, meeting friends

I'm the daughter of the person with dementia and I pay her rent, get her pension, and pay her bills. My own daughter helps me do her shopping. The person with dementia has stopped going to do all of the above and stays in a lot. Library, shopping, hence college (English class) once a week
 Shopping, visiting the library and classes
 I used to be a carer for my grandmother who had dementia and did all everyday tasks for
 Shopping, cafe
 Shopping, banking, library to Dementia café. Life Store for dementia group meeting. Visit parks, museums
 Shopping
 Like shopping over Teesside park
 Shopping - go to local seaside, local park
 Shopping, Saturday night goes to club, social
 Sports, walking
 Volunteering ranger for North York Moors (volunteered for over 22 years)
 Shopping, biking
 Football, going to the gym
 Walk in park, visiting cafes
 Walking, library, visiting friends
 Walking (hiking in the moors) football, history
 Walking socialising with friends, baking
 Local sewing club, badminton held in different locations, schools
 Don't do anything in local area
 None due time constraints when carer for husband with dementia
 Exercise classes
 Shopping and going out for meals and coffee
 Visiting the town to have a look around and get out of the house
 Shopping, keeping fit, gong to training at the local school
 Visiting our daughter in Newcastle, going shopping and attending support meetings.
 Walking the dog. There are no shops any more on our estate. They all shut down.
 Shopping, Cafe
 Viscent Library and Gutter Club
 Shopping, Café, Library and Banking
 Shopping and cafe
 Shopping
 Go shopping and attending football matches
 Shopping, Cafe
 Shopping, cafe
 Shopping, cafe
 Patrol Officer
 Shopping
 Shopping/café, sitting
 Working, shopping, walking dog
 Shopping, café, 1 pint
 Shopping - 6 groups. Walking. I.L.O.P now R.V.S lunch club - Tuesdays. Church quiz every fortnight
 Shopping, walking

Paying bills
Shopping, seeing friends
Just shopping. Once a month like to go to pub to socialise
Shopping, working, cafes/restaurants, socialising

4. Is there anything that helps you to do the things in Middlesbrough you enjoy?
For example clear signs, people to ask who understand about dementia,
good lighting or a comfortable seating area etc.

Go out with carer
Mother does go out, unless to center at North Ormesby day care. Good Lighting,
comfortable seats inside and outside centers. (People with dementia won't go in
lifts or escalators. Impossible to do this - maybe stair lifts installed.
Comfortable indoor seating areas
Lack of understanding by shop keepers
As mention in question 2 the person with dementia rarely goes out if she has been
agitated, then she can just go anywhere and the person with dementia is deaf too
so she is very vulnerable
Comfortable seating area, parks
No thing clear
Not aware of people with dementia awareness. More seating now in Malls but could
do with more in stores
Welcome all the above examples
I just go out with my wife, people seem helpful
Use of public transport to get to where I need to go
My wife helps me, without her I would not be able to access Middlesbrough Centre
Good lighting and access, people are very helpful with wheelchair
Local church hall holds sports activities
Being in good (relatively) health
Cycling paths for biking
Public transport when own transport is broken
Support from Carers Together (due to health problems)
Granddaughter encourages me to be active. Lovely places to walk, good
community.
Social club to watch football, job at library allows me to read history books
Not really
No
Lack of amenities
Public transport to meet sister town center is focus point for meeting sister
Asian specific exercise classes
My wife
There is a good bus service in Marton with wheel chair access-this makes getting
into town easier
Having people that know me well and about my dementia makes me feel safe
I am lucky that my wife Susan is my carer and gets me about. Found trusts provide
good service.
People who understand dementia.

Good lightening and seating area
 Lack of seating in shops
 N/a
 Clear signs, People to ask
 Clear signs, signposting to different shops
 Clear lighting
 People are friendly - advice and help given to many people
 Lack of understanding
 Comfortable seating
 Carer make life more comfortable
 Seating, clear signs and lighting
 All the above examples
 Good signage, comfortable seats
 Clear signs, people understanding dementia, lighting and seating
 Good lighting. Wider aisles for easy access. Wheelchair friendly shops and car parks

5. Is there anything that makes it more difficult for you to do the things you enjoy? For example a lack of understanding of dementia by shop keepers, problems using public transport, uneven flooring, or poor exit signs in shops etc.

People in general as they find her behavior aggressive (server dementia). Cannot use public transport, partial sight, slow on her feet
 Public transport daunting poor visible information at bus stops
 Worry of getting lost, people speak to you, lack of understanding by nearly everybody apart from the people that know you
 Uneven flooring for person with dementia that's why she won't go out much
 Nothing
 No
 There needs to be more understanding of how the condition effects people and more tolerance towards them
 Lack of understanding in shops. Public transport - good if 'Leven Buses' Stagecoach and Arriva - Often start before seated.
 No seating at Teesside Park
 Poor flooring trip hazard walking into Linthorpe village
 Paving stones can be difficult to push the wheelchair on them
 High cost
 Lack of mobility due to knee replacement (slightly restricted)
 Time constraints - carer for mother
 Expense
 Health problems (COPD)
 Arthritis depending on date. Can't swim temporarily due to bad health problems.
 Lack of public transport to hiking areas
 Lack of money
 No
 Like to go out of area
 Lack of support and respite when caring for husband, lack of time to begin social activities

No

Transport, poor exit signs in shops finding my way back from the toilet when I am in restaurants, cafes and pubs

Getting wheel chair and dementia friendly taxis and busses is difficult

A lot of people do not know enough about dementia I feel judged sometimes if I am a little slow

Don't drive anymore.

Using public transport and uneven flooring.

There's a lot of people don't understand about dementia. People in the community have little awareness.

Shop keepers not understanding my diagnosis

Wheelchair access in some shops and also more seating

Lack of understanding

Lack of public transport

Lack of understanding of dementia and what to do with person/persons

Struggling to use money

Lack of understanding by public

Patience from people, people don't seem to have the patience and understanding and don't want to assist, this is due to lack of understanding

Flooring, better hearing facilities

Uneven flooring

Impatient people who do not understand dementia

Better understanding of dementia by shop staff

More understanding of dementia from by services suppliers

Not enough seating for those who have difficulty walking in centers. Most are outside, lack of understanding in shops.

6. If you have stopped doing things in Middlesbrough why have you stopped doing them? Thinking about things such as how people spoke to you, the worry of getting lost, struggling to use money, lots of reflective surfaces and mirrors making it difficult to focus.

The carer tends to all the needs

Way people spoke to us, me & mother. Looks we get. My mother confused and shouts so if she is not picked up in a vehicle provided she does go anyway. Can't go on public transport, café bars, keep fit/dance classes. Had to stop all socialising as people just look at her and don't understand. So classed for people with dementia need to be put in place.

She's stopped doing them as she lost interest. Uneven pavements, plus deafness.

NA

No - if I have a problem, I usually discuss it with them

I am dependent on public transport

Haven't really stopped doing things

Haven't stopped doing my daily things yet

Things should be well advertised

Just don't engage with sports as much due to carer duties (look after parents and autistic son)

Not applicable
Lack of health related facilities to encourage physical activity
Health problems (COPD)
Use to bike but stop because roads are too dangerous. Swimming - too expensive, no swimming baths in Middlesbrough
Stopped being in a walking group in Middlesbrough. not allowed to access due to moving to Marsk
No
Don't like Middlesbrough area
Too busy with commitments
I do not go out alone so can only go when my wife is available
I use to just pop out when I wanted to see friends etc. but now it has to be planned
Going to the Little theatre getting there is a problem
Not practical to do as wife has macular degeneration
The wind blowing through the automatic doors
Owing to lack of walking ability to old age.
As I am always with my husband this is not applicable.
Cleveland centre hasn't enough seating
Cost of transport and Car Park
Require assistance
Shop keepers' awareness
People with dementia struggle on a daily basis, having done work with people.
Tolerance is the most important
Meeting people, not making myself understood, need more time to be understood.
Ok
Too loud music and lights in shops - still use them but start to feel ill and have to leave.
Walking
Cost of transport and car parking
Struggling with transport
Still shop in Middlesbrough

7. Is there anything which may help you start doing the things you liked but no longer do? For example more shop keepers with an awareness of dementia, a peer support, someone to accompany you, clearly signposted exits in shops etc.

The carer tends to all the needs
Yes - shopping with people with dementia is impossible (As she gets lost and generally confused) would be good to have company but my other (won't tolerate strangers) Maybe take her to public (Dementia cafe)?
I won't be able to do the things the person with dementia has because we been told she needs 24hr care EMI nursing she needs to go into a care home.
No
Increase the level of awareness about the disease by more workshops

It would be helpful in stores if there were signs - and designated staff - who other staff could direct you too.
 My mobility is a problem, more public seating
 Everyone to have understanding of dementia to stop people being unpleasant
 Better paving
 More support for parents - carer for both
 Not applicable
 Commitments stop him from travelling to visit friends
 More affordable health activities, more freebies
 More support to be active
 Losing weight, successfully doing that through checking weight in Life Store
 Swimming baths for Middlesbrough residents
 Not applicable
 No
 Like eating out and socialising, good range of restaurants
 Not appropriate
 Communities are not the same people come and go and don't get to know you so no support
 More accessible buses and training to drivers of buses and taxis
 More accessible buses with drivers knowing about dementia and how to help
 No
 Does not apply.
 Shop keepers should be aware of dementia
 Accompanying around shops
 Companionship
 More information from other agencies
 Make people aware
 If support groups would help i.e. buddy when going shopping
 More support in the community would be beneficial, most businesses have a first aider. It would be Nice to see business allocated a member of staff who understands dementia and be able to assist Individuals who do in the community
 OK
 Exits in shops
 Help from friends to go out and friendly helpful people
 All the previous, better transport and understanding
 Clearer signage in shops. More understanding of problems associated with dementia.

8. What do you think could be done to make Middlesbrough more dementia friendly?

Where do I start? Wheelchairs in shopping areas - shopping areas more seats, nothing in most center. Awareness of person's condition, my mother is confused but not stupid, so educate people who are in shops. Patience, understanding. Swimming classes to help them relax. More dementia café bars, keep fit, music, dance classes, bowls, relaxing tea rooms, parks, golf. Book clubs/newspaper clubs/memory games. Cake day - cooking skills one to one. Special groups to be

set up for people with condition to be separate - as old people/and general public do not understand

More tolerance by younger people

Yes

People should listen to the relative's views and concerns especially when they go to hospital. They should listen to relatives more as I feel we were let down by people not talking to us and listening more. Should have more information available or short advert on TV making people aware.

Speak more with people, raising awareness about dementia to BME communities

By more leaflets and workshops and classes

Education public, mail shots. More info displayed in libraries, doctor's surgery and other public places

The whole area to have a 'make over' such as sign posting - smooth pathways

I think these people need groups with activities, outings, etc. as they seem to like these things.

More awareness of dementia and how people can help individuals with dementia.

Not sure

Not sure - not much experience with dementia

More training for staff and general public

Not sure

Projects for people with dementia and their carers

Awareness of early warning signs and dementia awareness for public

Just use the Life Store- lovely service

Not sure

Not sure

Lack of training for staff in nursing homes and hospitals. Improving care for dementia patients in hospitals. No unit in Middlesbrough that qualifies for 24 hour nursing care for patients with late set dementia, only two in North East. Poor nursing care.

Greater understanding by all about dementia

Train all bus drivers and have more conductors who are dementia friendly

People with dementia being more honest and telling people they have dementia so they understand and give us time at check outs etc.

Educating the public about the problems dementia suffers have.

Talk - one under standing

Awareness

As above

Signage, accessibility, shopping with a support worker to help with money, access Regular meetings and info

Decent places for people who suffer from dementia take them somewhere for a cup of tea

There should be more help across the ageing population and it should be published were it is available.

Bring this into the public profile to make people aware of dementia

Easy for wheel chair access, dementia friendly shops

Quicker diagnosis and more help for them.

Develop it into Dementia Friendly town and with support/respite for carers of people with dementia

Staff training and taking time to serve and chat to people

OK

Training offered to shops to cover dementia awareness.

9. Please use this space to tell us anything else you would like to tell us about health and social care services you use. Is there anything that needs improving or is there a really good practice you would like to share?

Goo OT. Social services when person needs are met to stay at home (Social Worker) doctor. But people (Carers) need to know where a person with dementia can go to socialise out of the house - and still have some quality of life, as above. So not the only choice to go to a center or home for old people
My husband has dementia, we are in touch with Woodside who are helpful. We are in touch with Sanctuary support
Organise trips to places of interest with dementia friendly guides and transport to get there
More pay centers with loop systems for deaf people as my husband is very deaf and has two hearing aids and would very much like to go to a day center but most of them do not have a loop system so it is a waste of time him going.
I think there should be a small advert shown on TV about dementia. Poster in town areas, also letting people know where you may get help from.
My dentist sometimes are not very friendly and taking time to explain things or procedure to me. Would like someone with more patience
I want to improve the GP local services and appointments
We are involved with several groups. Forget-me-nots, Sanctuary - lunch club and monthly group meeting. Age UK - soup and social on Tuesday. There are so many things available - not always good information to early diagnosed clients
Social worker does a very good job
Not happy with mental health services. Bad services from Roseberry Park for friends and family. Not well equipped for adults with autism. Lack of communication between Lakeside and Roseberry Park.
Over the moon with treatments from James Cook Hospital with Bowel Cancer and two knee replacements.
GP- Endeavour practice, give good care, can always get appointment. Diabetes clinics good advice and support for diabetes care
Cancer testing
Only use Life Store to check weight, lovely service
Problems getting appointments at GP, works early morning so can't ring up at half 8 for appointments
No
Too difficult to get doctors' appointments
Difficulties getting doctors' appointments - can't get appointment in morning
Middlesbrough does very well to help dementia suffers but always room for improvement.
Use meetings with sanctuary and Woodside
None of the questions above relate to someone concerned about making Middlesbrough a dementia friendly town, but who currently does not have dementia, nor cares for someone with dementia.

DR First and ringing for appointment and getting the same day
 Better access and appointment system
 To learn how to make people feel comfortable, warm and safe. Being able to assist, funding, who carers or family care
 My friend Kev looked after his granddad for several years. I also helped to look after this man. I found they was very little help for Kev at the time as he used to get very tired of looking after his granddad. His granddad did get lots of support from his GP from the Newlands Medical groups.
 Really enjoy coming to Life Store, very helpful
 I changed doctors recently because of the excellent report I had - it took 2 hours on week to get through and 5 days another week to get a phone consultation! BT hogging the phone on 5 and virgin on 3!
 My doctor has Doctor First and now you can get an appointment on the same day.
 OK
 Although I don't live in Middlesbrough my parents do and I shop with them. I also work throughout the area with dementia clients.

7.2 Dementia Friendly Community Public Event Findings

Notes from the group exercises

Healthwatch Middlesbrough Dementia Friendly Community Event 11 June 2015

| Things that make it easy/better | Why? |
|--|--|
| | <ul style="list-style-type: none"> • Encourage independence |
| Things I struggle with or make it more difficult | What changes would help improve this? |
| <ul style="list-style-type: none"> • Lack of understanding • Overuse of technology everywhere • Inaccessible environments • Being rushed • Stressful situations for carers - leads to difficulty for person with dementia • Media - negative attitudes • Stigma • Not enough seating • Impatience | <ul style="list-style-type: none"> • Morrison's - very good in café • Community spirit - need more • Involving different cultures - awareness • Dementia Hub |

In order of importance

- Enable you to live well with dementia for as long as possible
- Educating people from young age - more open to dementia and changes for DF communities
- Raising awareness - starting point of it all!
- Making younger people more aware of dementia
- Dementia friendly trained staff e.g. care homes, shops buses, transport
- Post Offices - staff more aware
- Community Awareness
- DFC Awareness - drop in centres
- Support for carers - understanding of their needs
- People who understand the difficulties I have
- Dementia training
- Basic empathy
- Remain and maintain a 'normal' life and don't become socially excluded
- More seating in shopping centres/town centres to enable independence eg. Not having to rely as much on wheelchair
- Safe local environment
- More safe spaces
- Safe Places Scheme - logo
- Signage - clear signs that make it easier to navigate/orientate around areas
- Sharing responsibility between statutory/non statutory organisations
- Dementia Friendly stations and transport
- Supermarkets - buy in from store
- Dementia friendly check out staff
- M&S very good
- More table service in coffee shops
- To make things less stressful for the person with dementia and their carers

| Things that make it easy/better | Why? |
|---|---|
| <ul style="list-style-type: none"> • People training - public services E.g. Post office, bus drivers, volunteers, shop assistant • Promote in local newspapers, radio etc. - Safe places - No. of dementia patients • Dementia Friends champions (in training programme) • Prominent signage - Dementia Friends flower | <ul style="list-style-type: none"> • Build network of support to allow people living with dementia (and carers) to maintain level of independence • So we know what Middlesbrough has to support people/raise awareness • Improve support • Raise awareness |
| Things I struggle with or make it more difficult | What changes would help improve this? |
| No responses | No responses |

In order of importance

- People training (Public services)
- Dementia Friend Champions
- Growing number of safe places to ensure improved network
- Create quality assurance standard e.g. embedded into IIP
- Promote locally in
 - Newspapers
 - Radio
 regarding safe places and number living with dementia
- Prominent signage e.g. Dementia Friend Flower
Stickers on each till point

| Things that make it easy/better | Why? |
|--|---|
| <ul style="list-style-type: none"> • Bus driver awareness - appropriate parking at bus stops (no gap) • Good availability of buses - lack of coverage in some areas • Bus timetable - bigger print, easier to understand • Dementia cafes • M&S great - lots of space to sit down | <ul style="list-style-type: none"> • Good transport links |
| Things I struggle with or make it more difficult | What changes would help improve this? |
| <ul style="list-style-type: none"> • Lack of IT awareness • Reliance on email to contact agencies • More places to sit to rest when walking • Lack of knowledge about community activities - need to promote • Big shops - difficult to find things, takes too long | <ul style="list-style-type: none"> • Better awareness of safe places - Life store to promote on big screen. Could promote through dementia cafes. • Design 'Safe Places' leaflet • Train 'Dementia Champions' in local areas to give out information • Produce local directory of dementia friendly services • Dementia trained staff in Tesco Stockton. Will sit with dementia person while carer shops |

In order of importance

- Emergency support - someone to contact when help needed when out of the community e.g. if person with dementia refuses to leave shop or walks off.
- Dementia friends training to people in the heart of the community so they can offer support and information locally.
- Spread awareness of dementia to LA staff, shops etc.
- General public awareness of dementia.
- M&S has seats inside which is really useful - more seats inside shops and in Hill Street Centre.
- Recognisable certificate and symbol in shop windows, dentists, opticians 'dementia Friendly'.
- Dementia Cafes are really good.
- Seating areas in community so we can sit down whilst trying to keep active.
- Joined up information sharing
- Dormans museum - what is going on, when and where - through my door on a regular basis.
- Safe scheme in Middlesbrough
- Needs to be expanded/promoted
- Care package to promote it
- How I would like to find out about Safe Scheme members
- Through my door
- Libraries
- GP
- Dementia cafes
- Leaflets
- I cannot find info as I cannot use IT
- Transport - kerbs high enough to get on - make sure you pull up against the high kerb
- On line training for carers so we can find information - would need sitting service
- Dementia Friends - shopping helpers to either show me round or sit with my wife whilst I rush round
- Not enough buses run around Middlesbrough - especially to the hospital
- Routes changing causes confusion
- Large print time tables with pictures etc. to make easy to understand

| Things that make it easy/better | Why? |
|--|---|
| <ul style="list-style-type: none"> • Cards that explain dementia (for carers to share) • Town maps highlighting facilities • Taunton - Purple Angel scheme (businesses to support dementia) • Football Clubs • More changing places • Make it regulated - once people have signed up • Ongoing change/support • Radar Key - can get - Shop Mobility, Hill Street | <ul style="list-style-type: none"> • Spread awareness - town centre, Middlesbrough retail meeting. • Understanding • Reduce Stigma • Support Carers • Directory of walks - route highlighting practical facilities • Staff awareness - all businesses |
| Things I struggle with or make it more difficult | What changes would help improve this? |
| <ul style="list-style-type: none"> • Signage/Public Toilets • Hospital signs good • Make male/female distinct | <ul style="list-style-type: none"> • Take music off when people talking ie TV • Training must happen more than Dementia Friends <ul style="list-style-type: none"> - practical - how to converse triggers • Secret shoppers check they are following pledges |

In order of importance

- Staff training - more than dementia
- Maps in town where services are
- Radar key awareness
- Assistance Prompts (contacts) CARDS spreading awareness
- Directory of routes (shopping etc.)
- Signage
- Secret Shoppers
- More changing places
-

| Things that make it easy/better | Why? |
|---|---|
| <ul style="list-style-type: none"> • More knowledge of resources, bridge cards etc. (training). • No cold calling zones • Toilet facilities - use of colours • Quiet areas of shopping centre/public areas • A calmer approach to situations | <ul style="list-style-type: none"> • Some bus drivers etc. may not have knowledge of what the cards are for. • Reduce chance of exploitation • Make it obvious • To bring down over stimulation • Calm possible aggression |

| Things I struggle with or make it more difficult | What changes would help improve this? |
|--|---|
| <ul style="list-style-type: none"> • Websites • Doctor surgeries - key link • Possible exploitations • Isolation | <ul style="list-style-type: none"> • Less complicated - FAQ • More info at diagnosis and beyond |

In order of importance-

- Build dementia training into qualifications in customer service etc.
- Discreet information card to use in shops etc.
- Sign up, where we are now, what helps, evaluation ,move on if necessary
- Consistent offer of support from GP's, volunteer orgs etc.
- Risk assessment at diagnosis
- More info at GP's at diagnosis from day 1
- Vulnerable to callers (financial exploitation)
- Not being able to leave people at home alone
- People with dementia are vulnerable when in community alone
- Assistive technology - don't always know what it is e.g. pull cords
- Having somebody with me to go places/offer support
- Crossing the road
- Assistance/concession for carer on bus e.g. hospital appointments
- Better publicity - register of carers/service users to send information to.
- Getting support from community e.g. dementia cafes
- Having information about what is available
- Difficult to identify things - want to do and to get there
- Meeting with other people and sharing similar experiences
- Learn from each other
- Dementia cafes - simple, cosy, useful
- Having means to be independent
- Managing money on practical level also paying for services
- Low cost/free activities - good value as opposed to those charged for by Social Services
- Can be isolating - Social Services provision can be expensive (day care)
- Support/care being offered when needed
- Social services - difference of opinion
- People not in a position to give up work to provide care (emotional impact - guilt)
- People can understand and provide support
- Personal care needs
- Progression of disease adds to carer burden
- Private people
- Dementia awareness for all

- Keeping two homes going at the same time. (Different areas transport costs)
- Carer trying to do shopping and care for somebody with dementia at the same time
- Other things (physical condition) that impact in addition to dementia

Pledges

| Organisation/contact person | Pledge | Comments |
|---|---|--|
| Middlesbrough and Stockton MIND Ageing Better, Michelle Dawson | To link in with all the work relating to this agenda as Ageing Better develops. To make sure Ageing Better Projects are dementia friendly and have good links with and understanding of how to support people with dementia and their carers. | |
| The Trinity Centre, Heather Black | Work with churches to help them become more dementia friendly. | Good to meet with lots of other people to talk about dementia. |
| The Life Store, Lynne Blackburn | To provide a training room free of charge to businesses in Middlesbrough to train staff in becoming dementia friends. | |
| Marks and Spencer, Steve Field and Debbie Clarke | To get message to new members of staff. To make staff aware we are part of the Safe Place Scheme and remain Dementia Friendly. | |
| C McCormack, Social Work student | | I am currently studying a social work degree at Teesside University just going into my final 3 rd year. Learning to understand dementia and their family's needs are very important to me. Also raising awareness I |

| | | |
|---|---|-----------------------------|
| | | feel very passionate about. |
| Age UK Teesside, Rebecca Fisher | To ensure that all services provided by Age UK Teesside are accessible and dementia friendly for those living with dementia and their carers. This includes making changes to our work/activity room environments to ensure these are dementia friendly including improved signage and colour contrast. | |
| Carers Together, Sarah Burnston and Edd Harford | Work collaboratively with Middlesbrough to make South Tees more dementia friendly. Support the development of DF Middlesbrough. | |
| Name not provided | I will help raise awareness by delivering dementia friends sessions. | |
| Name not provided | To link in with local dementia activity services and carers groups to offer know your own blood pressure info and advice. To signpost to Alzheimer's Society | |
| Middlesbrough Central Library, Diane Fleet | To extend dementia cafes to all libraries To become a dementia champion To promote Books on Prescription library service to all Middlesbrough GP's. | |
| Name not provided | Work with the Safe Places Scheme to develop and promote the scheme further (MBC and Press Office | |

8. References

[1] - Department of Health. (Feb 2015). Prime Minister's challenge on dementia 2020. Available: <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020>.

Last accessed: 09/10/15

[2] - Kirkwood, T. (2012). The North East Charter for Changing Age. Available: <http://www.yearsahead.org.uk/reports/northeastcharterforchangingage/>.

Last accessed 09/10/15.

[3] - Smith, D. and Otter, P. (July 2014). Dementia 2014: A North East Perspective, Northern Rock Foundation. Available: <http://www.nr-foundation.org.uk/downloads/Full-Report.pdf>. Last accessed 09/10/15.