

Dementia Services Action Plan

2011-2014

Report Version 2

Thurrock Adult Social Care

DRAFT

Contents

1. Introduction	3
2. The National Context	3
3. Dementia Alliance Declaration	4
4. NICE Quality Standards	5
5. The Local Context	5
6. People living with dementia in Thurrock	6
7. Where we are now	10
8. Summary	12
9. Action Plan	13
10. Appendices	
Appendix 1 - National Dementia Strategy Objectives	26
Appendix 2 - National Dementia Declaration Outcomes	29
Appendix 3 - NICE Dementia Quality Standards	32
Appendix 4 – Quality Outcomes for People with Dementia – building on the NDS	33
Appendix 5 – Thurrock Council’s dementia consultation	35

1. Introduction

The Dementia UK report (2007) identified that one in 20 people over 65, and one in 5 over 80, are affected by dementia. In Thurrock, estimates indicate that more than 1400 people have dementia rising to more than 2600 in 2030.

Working with health and social care partners across Essex we have looked at 5 key areas that will enable us to significantly enhance the quality of outcomes for people who use services:

- Join up Health, Social Care, Independent, Private and Voluntary sectors to provide a seamless equitable service
- A strong focus on the shift of provision to early intervention and prevention
- Provide personalised support in the community that reduces admission to acute hospitals and residential settings
- The provision of information, advice and support are consistent and available at the time the person needs it
- Ensure that those working with people living with dementia and their carers have the appropriate skills and knowledge required to provide a quality service.

There are clear links within this action plan that refer to other work around End of Life, Carers and Disability Strategies as well as the Workforce Plan.

2. The National Context

The National Dementia Strategy (NDS) launched in February 2009 is a 5 year plan that was aimed at helping people to live well with dementia. In order to achieve this vision 17 objectives were identified specifying improvements of 3 key areas.

- Raising awareness
- Early diagnosis and intervention
- Living well with dementia

On 8 September 2010, the Department of Health published a revised, outcomes-focused implementation plan for the National Dementia Strategy. *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy* updates the previous implementation plan for the Strategy, which was published in July 2009. It is aimed at accelerating the pace of improvement through a greater focus on local delivery and local accountability and empowering citizens to hold local organisations to account.

The implementation plan sets out the Department's four priority objectives for securing improvements in dementia care:

Early diagnosis and support – Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GP's feel they have adequate training in diagnosis of dementia.

Improving the quality of acute hospital care - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co morbidity with general medical conditions is high, people with dementia stay longer in hospital.

Improving care home quality - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

Reducing the use of antipsychotic drugs - There are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription.

All of these are to be underpinned by personalisation and personal support in the community. Improved community support services are integral in each of the four priorities as they support early intervention; prevent premature admission to care homes and impacts on appropriate admission to hospital and length of stay.

3. Dementia Action Alliance Declaration

The Dementia Action Alliance was launched on 26th October 2010. The Alliance is a coalition of 45 organisations led by The Alzheimer's Society and supported by Department of Health to develop a National Dementia Declaration. The Declaration is a call to action to improve the quality of life outcomes for people with dementia and their carers. On launch the Alliance published a national Dementia Declaration explaining the outcomes they will seek for people with dementia and their carers and the actions they intend to take in order to help deliver those outcomes. The seven agreed outcomes come under the following headlines.

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs
3. I have support that helps me to live my life.
4. I have the knowledge and know-how to get what I need

5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future.

See Appendix 2 for further details

4. NICE Quality Standards

NICE quality standards defines a high standard of care within dementia care. It provides specific, concise quality statements, measures and audience descriptors to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

See Appendix 3 for full details

5. The Local Context

Thurrock Council's Corporate Plan and Community Strategy sets out a clear vision for Thurrock:

We want Thurrock to be at the dynamic heart of the Thames Gateway, a place of ambition, enterprise and opportunity, where communities and businesses flourish.

Our priorities within the community strategy are:

1. Improve the education and skills of local people.
2. Encourage and promote job creation and economic prosperity.
3. Ensure a safe, clean and green environment.
4. Provide and commission high quality and accessible services that meet, wherever possible, individual needs.
5. Build pride, respect and responsibility in Thurrock's communities and its residents.

Our aim is to become a confident, well managed and influential Council regarded by residents, peers and partners as ambitious for the people of Thurrock and totally focused on meeting their current and future aspirations.

Although achieving all five priorities are essential to people with dementia in Thurrock and enjoying a good quality of life both now and in the future, particular emphasis can be placed on priority four. This is demonstrated as follows:

1. Reduce inequalities in health and wellbeing
2. Support families in need and intervene to protect vulnerable children and adults
3. Enable vulnerable people to exercise choice and control
4. Change the way we do things to reduce costs and improve choice

6. People living with dementia in Thurrock

Thurrock currently has a population of just under 160,000. There is a predominately younger population in the borough, particularly within the areas of Tilbury and St Chads, Chafford and North Stifford, South Chafford and Thurrock West and South Stifford. Thurrock's older population is smaller as a percentage of total population than both England and the CIPFA comparator groups and populates the north of the borough in areas such as Orsett, Corringham and Fobbing.

The population is projected to grow by 28% or 44,242 additional people by 2031. As life expectancy continues to increase, Thurrock will see a significant ageing of its population. By 2033 the population group aged 85 plus is expected to double.

Headlines – Older People

The increase in the Older People population will present a huge challenge to commissioners and service providers in meeting the needs of people with dementia. Projections for Thurrock indicate an increase as set out below:

Table 1 – Predicted population 65+ for Thurrock

	2011	2015	2020	2025	2030
People aged 65-69	6,600	8000	7200	7900	9500
People aged 70-74	5100	5700	7300	6600	7300
People aged 75-79	3800	4400	5000	6400	5900
People aged 80-84	3000	3000	3600	4100	5400
People aged 85-89	2000	1900	2100	2600	3000
People aged 90 and over	1000	1300	1600	1900	2400
Total population 65 and over	21,500	24300	26800	29500	33500

Table 2 - Population projections for people in Thurrock aged 65+ by age band and gender

Dementia by gender	2011	2015	2020	2025	2030
Males aged 65-69 predicted to have dementia	48	60	51	59	69
Males aged 70-74 predicted to	71	84	109	93	109

have dementia					
Males aged 75-79 predicted to have dementia	87	97	112	153	133
Males aged 80-84 predicted to have dementia	112	122	153	184	245
Males aged 85-89 predicted to have dementia	117	117	134	167	200
Males aged over 90 predicted to have dementia	84	112	140	167	223
Total males aged 65 and over predicted to have dementia	519	592	698	823	979

Dementia by gender	2010	2015	2020	2025	2030
Females aged 65-69 predicted to have dementia	35	41	38	40	49
Females aged 70-74 predicted to have dementia	67	74	91	86	91
Females aged 75-79 predicted to have dementia	143	163	182	228	215
Females aged 80-84 predicted to have dementia	239	239	279	319	399
Females aged 85-89 predicted to have dementia	289	289	289	355	400
Females aged over 90 predicted to have dementia	215	276	338	399	491
Total females aged 65 and over predicted to have dementia	988	1082	1217	1427	1645

Total population aged 65 and over predicted to have dementia	1507	1674	1915	2250	2623
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Headlines - Other high risk groups.

Younger people with dementia

Although the numbers of younger people developing dementia are low, they can face quite different needs. At the time of diagnosis they can still be in work, have dependent children and heavy financial commitments, such as a mortgage.

Table 3 - Projected population figures for 18-64 in Thurrock

	2011	2015	2020	2025	2030
People aged 18-24	14100	14100	13900	14400	16200
People aged 25-34	24000	26300	27800	27500	27000
People aged 35-44	25600	25300	26400	29000	30200
People aged 45-54	21800	24400	25400	25000	26100

People aged 55-64	17200	16900	19500	22500	23200
Total population aged 18-64	102700	107000	113000	118400	122700

Table 4 - Early onset dementia – Populations projections for people in Thurrock under 65 by age band and gender

Dementia by gender	2011	2015	2020	2025	2030
Males aged 30-39 predicted to have dementia	1	1	1	1	1
Males aged 40-49 predicted to have dementia	3	3	3	3	3
Males aged 50-59 predicted to have dementia	10	12	14	14	15
Males aged 60-64 predicted to have dementia	9	7	9	10	11
Total number of males predicted to have dementia	22	23	26	29	30

Females aged 30-39 predicted to have dementia	1	1	1	1	1
Females aged 40-49 predicted to have dementia	3	3	3	3	3
Females aged 50-59 predicted to have dementia	7	7	9	9	9
Females aged 60-64 predicted to have dementia	5	5	5	6	7
Total number of females predicted to have dementia	16	17	18	20	21

People with a learning disability

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:

- 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 (eg 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.

People with learning disabilities have an increased risk of developing dementia as they age than others. People with learning disabilities also generally develop dementia at a younger age. This is particularly the case for people with Down's syndrome: one in three develop dementia in their 50s.

Studies suggest the numbers of people with learning disabilities other than Down's syndrome who have dementia are 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. Genetic factors may be involved, or a particular type of brain damage associated with a learning disability could be a cause.

Down's syndrome and dementia

When people with Down's syndrome develop dementia, this is usually due to Alzheimer's disease. However there is a growing awareness that people with Down's syndrome can develop other forms of dementia.

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.

These numbers indicate a greatly increased risk for dementia compared with the general population. Studies have also shown that in later life almost all people with Down's syndrome develop the changes in the brain associated with Alzheimer's disease, although not all develop the symptoms of Alzheimer's. The reason for this has not been fully identified. However, it is known that the protein that causes brain cell damage in Alzheimer's disease is produced from a gene on chromosome 21. People with Down's syndrome have an extra copy of this chromosome, which may largely explain their increased risk of developing Alzheimer's disease.

The symptoms of dementia in people with Down's syndrome are broadly similar to those in the general population, although there are some differences. Changes in behaviours or personality (e.g. becoming more

stubborn, irritable or withdrawn) are more often reported as an early symptom of Alzheimer's than memory loss.

People with Down's syndrome are more prone to fits than others. However, epilepsy that appears in someone with Down's syndrome later in life is almost always a sign of dementia and should be investigated thoroughly.

The middle and later stages of dementia in people with Down's syndrome are similar to these stages in the general population. However, there is some evidence that dementia in people with Down's syndrome progresses more rapidly.

7. Where we are now

Services for people with dementia in Thurrock are delivered by several organisations including Thurrock Council, NHS South Essex, Basildon and Thurrock University Hospital and the Independent and Voluntary Sector, who provide, or are commissioned to provide, a range of services and support to people living with dementia and their carers.

Throughout the development of this action plan we have listened to people with dementia and their carers. Below is a snap shot of some of the things, both positive and negative, that people have told us.

'Carers feel isolated. Although I have contact numbers I feel by the time I have made contact the crisis will have passed. Regular contact may help'

'I am 91 years of age and apart from visiting my GP and obtaining a Blue Parking card, wheelchair and pendant alarm have never been offered any assistance. Looked after my wife until recently but she's now in a care home. Being well cared for, thank god'

'I have had to fight for my mum to be diagnosed and to seek all the relevant agencies on my own (my mum is only 66)'

'It would be good if you could offer support as and when needed, as just getting a medication dispenser was a complete nightmare. It took me weeks and weeks to finally get it set in place. I can't remember how many phone calls I had to make. I was very disappointed and frustrated at the service I received.'

'The Alzheimer's Society and its website are excellent. The two support worker ladies, who came to me without being asked, constantly ask if I'm OK and when it's 'no' they help, advise and nag perfectly'

'I went to the Alzheimer's Society who put me in touch with the local group. I found the GP's to be unhelpful, not interested, negligent. Alzheimer's Society in Thurrock is brilliant'

'At first I didn't realise that my husband was suffering from dementia until doctors diagnosed him as he has speech impairment due to stroke.'

'Thurrock Council provides a very good service for carers'

'I think it would be good to have more information about dementia at local libraries'

'Thurrock Mind advocacy service has been helpful'

'More coffee mornings would be good for my dad and give him something to look forward to and someone else for him to talk to. It would also give me a break for a while'

'Need to make sure the family have all the information available, every step of the way to fully understand what is going on'

'Information on early signs that suggest dementia might be the cause of a person's illness should be put up in every GP surgery, hospitals and council office (it took 6 months of unhappiness before my wife and I realised)'

'Training is important for carers, hospital staff etc. Posters displaying what dementia sufferers can expect'

Listening to these and many other comments has helped to shape this action plan. Of the 6 key priorities set out within the Essex, Southend and Thurrock Dementia Strategy, 48% of people said that the top priority should be around access to information and advice.

When asked which services would be helpful for people living with dementia and their carers 24% responded with respite care and 16% again highlighted the importance of information and advice.

8. Our Commissioning intentions and priorities

Following public consultation on the Essex, Thurrock and Southend Dementia strategy 95% of respondents agreed with the six priorities that have been identified for 2011 to 2014. The priorities set out below are in the order that the people of Thurrock felt were most important.

- 1) Ensuring clear pathways are available for all people including those with young onset dementia or learning disabilities to access timely assessment, diagnosis, treatment and support.
- 2) Access to admission avoidance schemes, reablement and intermediate care
- 3) An effective, trained and skilled workforce.
- 4) Appropriate support to carers and recognition of carers as partners in the care of people with dementia,
- 5) Enhanced liaison and in reach services to acute hospitals and nursing homes which includes strategies to reduce the use of anti-psychotic medication.

- 6) Access to palliative care and support to people with dementia at the end of life.

9. Summary

This document sets out the approach to ensuring that in Thurrock, services for people living with dementia and their carers meet the outcomes that people with dementia have identified are important to them. It sets out some actions to ensure a difference is seen by people living with dementia and carers. We have used the priorities identified in the Essex, Southend and Thurrock Strategy and NDS draft quality outcomes to steer our action plan and measure progress.

A key delivery mechanism for many of the actions will be via the Older Adult Mental Health Programme Board, which is an Essex wide group including key partners in health and social care. To ensure that actions are delivered on target a Mapping and Progress Report will be updated at 6 months for the first year and annually thereafter. Locally this will be monitored by Thurrock Older People's Partnership Board Executive Group.

Action Plan

Key: **PCT's** – Primary Care Trusts, **MHT's** – Mental Health Trusts, **ASC** – Adult Social Care, **OMT** – Operational Management Teams, provided jointly between Thurrock Council and South Essex Partnership University Foundation Trust Foundation Trust (Sept) **CT** – Commissioning Team, **OAMH ws** – Older Adult Mental Health Programme Board work stream, **WFP** – Workforce Planning

Outcomes and Descriptors are from the DH, Quality Outcomes for people with Dementia: building on the work of the National Dementia Strategy Sept 2010 Each statement has links to the relevant National Dementia Strategy (NDS) Objectives, National Dementia Declaration (NDD) outcomes and the Nice Quality Statements (QS).

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
<p>Outcome 1. I was diagnosed early. <i>People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.</i></p>					
Memory service operates in Thurrock	Provision of a memory service which is age inclusive and has the capacity to take all appropriate	Develop preferred outcomes and define delivery needs for memory services for people with dementia and their carers within the community	PCT supported by Thurrock Council	TBC	
		People will have access to rapid and good quality specialist dementia diagnostic assessment across the borough in keeping with the national model.	Memory Services	April 2012	
		Memory services to explore and develop ways to actively	Memory Services	Ongoing	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
<p>The National campaign is raising awareness of dementia to the general population. Locally Alzheimer's Society is funded to provide many services including information and advice to people in Thurrock.</p>	referrals.	identify people at risk of developing dementia	PCT's		
	<p>All information is accessible in a variety of formats, is clear and easy to read</p>	<p>Improve quality of recording across organisations to inform progress, future need, unmet need and the Primary care QOF register</p>	All NHS LA's	TBC	
		<p>We will ensure that there is accessible information about dementia within Council buildings and it's website to encourage people to recognise the signs and symptoms of dementia in order to seek early diagnosis.</p>	CT	April 2013	
	<p>Staff working with older people, people with learning disabilities and others at risk of</p>	<p>Training to be available for all front line staff to recognise early symptoms of memory problems in order to promote early diagnosis, and to understand options available to support people living with dementia and their carers</p>	Workforce development	TBA following training review	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
	problems, to promote early diagnosis, to understand support options available	We will target key groups on awareness raising such as BME groups and those with a learning disability	Workforce planning	TBC following training review	
<p>Outcome 2. I understand, so I make good decisions and provide for future decision making. <i>Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.</i></p>					
There is a variety of information available but 48% of respondents to the consultation said it was quite difficult to find.	To have accessible information available at the appropriate stage of the illness	We will look at options for one point of contact in Thurrock, linking with all partner organisations. People affected by dementia and those who work with them will know where to get information, advice, and access to resources in their area.	CT	March 2012	
		Enable Peer Support groups and networks to be involved in the development of the Strategy and Services for people with Dementia and their Carers	CT	Ongoing	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
		Implement CQC recommendation: 'Ensure that older people and their carers are provided with information and support when they are discharged from hospital'	OMT	April 2012	
		We will develop with partner agencies an Essex wide website which contains all dementia related information for people with dementia and their carers.	CT	Dec 2012	
		We will ensure that advocacy is available to those in need to ensure decisions are appropriate and in the person's best interests.	CT	2011	
		We will support people with dementia to access mainstream services within Thurrock, monitoring contracts against The Equality Act 2011	Contracts team	January 2012	
		Every service user at diagnosis will be offered the support of a dementia advisor for future access	Memory Service	April 2012	
		Local information packs for service users to be provided at diagnosis which includes information on the illness, treatment and clear person centred pathway services.	Memory service	January 2012	

Outcome 3. I get the treatment and support which are best for my dementia, and my life.

Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
<i>choice in social care and ongoing support will be of a high quality</i>					
<p>There is a good range of innovative services across Thurrock with real progress being made on implementing the above objectives of the NDS. However, these are fragmented and inconsistent.</p> <p>Assistive technology for people with dementia can promote greater independence and reduce risk, but is currently</p>	<p>People living with dementia in Thurrock will be able to receive personalised services that meets their needs</p>	<p>We will develop a joint workforce planning and dementia training strategy in line with the dementia training strategy being developed with Essex CC</p>	<p>WFP</p>	<p>TBC following review</p>	
		<p>Develop a Dementia Intensive Support team (DIS) in the community which offers alternatives to hospital pathway and evaluate the outcomes of the pilot.</p>	<p>PCT/CT</p>	<p>August 2011</p>	
		<p>We will undertake a gap analysis of local market to inform current gaps in existing provider provision.</p>	<p>CT</p>	<p>Ongoing</p>	
		<p>Explore options for night time support services for people with dementia to provide essential support to remain living at home</p>	<p>CT/OMT</p>		
	<p>Assistive technology is embedded in the self directed support service</p>	<p>Promote the use of Assistive technology for people with dementia and their carers and provide information at point of diagnosis for early intervention</p>	<p>Telecare Specialist Practitioner</p>	<p>March 2012</p>	
		<p>Continue to fund the Alzheimer's society in Thurrock to raise awareness of dementia across the borough and reduce stigma</p>	<p>CT</p>	<p>Ongoing</p>	
		<p>Review and reduction of inappropriate prescribing of anti psychotic medication within care homes.</p>	<p>PCT</p>	<p>Ongoing</p>	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
underused.		Safeguarding – continue to develop practice and process around Safeguarding, Deprivation of Liberty and Mental Capacity Act, in line with locality Safeguarding actions plans and CQC recommendations.	OMT	Ongoing	
		Increase in capacity to enable greater access to intermediate care services for people with dementia.	OMT	April 2012	
		Reduction of inappropriate admissions and readmissions to acute hospital for people living in care homes with dementia and training for staff.	PCT	Ongoing	
<p>Outcome 4. I am treated with dignity and respect. <i>People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.</i></p>					
Where are we now? There has been a considerable increase nationally in media coverage highlighting the	We know we need to do more and build on the national campaign and raise	Ensure staff promote the use of 'This is me' doc. to improve hospital care. http://alzheimers.org.uk/site/scripts/download_info.php?fileID=849	Contract team	January 2012	
		We will continue to Promote Dignity Awards in residential and Domiciliary Care settings within Thurrock	Contracts Team	December 2011	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
needs of people with dementia which is helping to reduce stigma. Local dignity group co-chaired by Thurrock Council and Thurrock Links. Dignity awards incentive for providers to excel in this area	awareness and understanding of the effects of dementia to reduce stigmatisation	We will ensure that staff working in social care have an understanding of dementia and how to support people living with dementia and then roll this out to the private, voluntary and independent sector	Workforce planning	TBC following training review	
		We will ensure that staff across adult social care know where to go to get the information and advice they need by providing experts within teams.	OMT	March 2012	
		Continue to fund the specialist voluntary sector organisations within Thurrock to raise awareness of dementia across the borough and reduce stigma in Thurrock	CT	December 2011	
		We will work with the emerging Clinical Commissioning Groups to ensure that dementia remains high on the agenda	CT	April 2013	
<p>Outcome 5. I know what I can do to help myself and who else can help me. <i>People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.</i> NICE QS 1, 3, 4, 5</p>					
Where are we now?	Where are we now?	We will promote the use of personal budgets	OMT	April 2012	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
Thurrock Adult Social Care provides Self directed Support and personal budgets (PB'S), however take up for people with dementia remains low.	We need to ensure that we maximise the use of Personal Budgets and Direct Payments to support people to manage the effects of dementia	We will ensure that people with dementia are able to access reablement services	CT	April 2012	
<p>Outcome 6. Those around me and looking after me are well supported. <i>People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.</i></p>					
With nearly 1 in 9 of the UK's carers looking after someone with dementia, this is a	Meeting the needs of carers is a high priority for Thurrock. To do this we	An annual carers survey is introduced to inform the service	Carers Strategy Officer	April 2012	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
significant group of carers whose needs should be better catered for.	recognise that we need to ensure carers are provided with quality, consistent, information and support at the right time	Carer awareness training is a fundamental part of regular training provided to new and existing staff	WFP	Ongoing	
		Support good quality information and advice to carers of people with dementia at first point of contact	OMT/WFP	Ongoing	
		Ensure carers of people living with dementia are fully included in all areas of the Thurrock Carers Strategy	Carers Strategy Officer	2012	
		We will provide information on how personal budgets can be used creatively to enable carers to improve quality of life outside of their caring role	OMT/WFP	2012	
		Health and Social Care managers should ensure that the rights of carers to receive an assessment of needs as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 are upheld.	OMT	2012	
		Support the development of Peer Support groups for people with dementia and their carers	CT	April 2012	
<p>Outcome 7. I can enjoy life. <i>People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.</i></p>					

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
<p>Where are we now? In Thurrock there is a focus on increasing access to supported housing for people with dementia to maximise independence and social inclusion. For example Elizabeth House scheme with Hanover Trust.</p> <p>People with dementia and carers are supported with social activities by the local Alzheimer's</p>	<p>People with dementia to be able to live in extra care housing which can be a home for life.</p> <p>Expand the support people with dementia can access in their own communities</p>	<p>Improve access to supported housing for people with dementia and their carers – ensure that people with dementia are not excluded from extra care housing schemes e.g. Elisabeth gardens</p>	<p>CT</p>	<p>Sept 2012</p>	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
Society.		We will continue to provide funding to the Alzheimer's Society to enable them to provide community based activities with people with dementia	CT	Ongoing	
<p>Outcome 8. I feel part of a community and I'm inspired to give something back. <i>People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research.</i></p>					
<p>Where are we now? We need to actively focus on research to inform practice and models of service delivery for people affected by dementia.</p>	<p>To keep up to date with recent research developments</p> <p>People with</p>	<p>We will regularly review National best practice around dementia, disseminate this information to staff and providers and encourage to put into practice</p>	CT	Ongoing	

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
We also need to change the perception of people with dementia being dependent, to one of maximising skills to engage in meaningful activities in the community.	dementia are able to fulfil an active role within their communities	We will encourage the setting up of peer support networks through the Alzheimer's Society.	CT	March 2012	
		We will continue to support existing projects such as the keep fit group provided by the Alzheimer's Society	T	Ongoing	
		We will ensure that people with dementia and carers are actively involved in the consultation and design of new services	CT	Ongoing	
		We will promote volunteering opportunities for people with dementia and their carers	CT	March 2013	

Outcome 9. I am confident my end of life wishes will be respected.

People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.

NICE QS 5, 9

Benchmarking - where are we now?	Where do we want to be	Action Plan	Lead or owner	Target Date	Outcome Achieved (including date) linked to Mapping and Progress Report
Where are we now? In Thurrock there is an End of Life Action Plan that is being developed in conjunction with Essex County Council	People will be able to end their lives with dignity. Maximised use of palliative care networks to ensure best practice	As part of contract monitoring ensure all providers have the 'Preferred Priorities List'	Contracts Team	May 2012	
		Advance care planning to be initiated or offered when diagnosis is made by memory service	Memory service	May 2012	
		We will ensure people with dementia have access to Independent Mental Capacity Advocates to ensure that right decisions are made and recorded.	OMT	Ongoing	
		We will ensure that end of life care in dementia is fully integrated into end of life care pathway and therefore people will have access to specialist palliative care	PCT	Ongoing	

Appendix 1

National Dementia Strategy Objectives

The key objectives of the Strategy, addressed in more detail in the full document, are as follows:

Objective 1: Improving public and professional awareness and understanding of dementia. Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

Objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

Objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

Objective 5: Development of structured peer support and learning networks.

The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

Objective 6: Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

Objective 7: Implementing the Carers' Strategy. Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs

and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

Objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes by the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

Objective 13: An informed and effective workforce for people with dementia.

Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

Objective 14: A joint commissioning strategy for dementia. Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy.

Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.

Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

Objective 16: A clear picture of research evidence and needs. Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.

Objective 17: Effective national and regional support for implementation of the Strategy. Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

Objective 18: Reduction in the use of antipsychotic drugs for people with Dementia.

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Appendix 2

National Dementia Declaration Outcomes

1. I have personal choice and control or influence over decisions about me

- I have control over my life and support to do the things that matter to me.
- I have received an early diagnosis which was sensitively communicated.
- I have access to adequate resources (private and public) that enable me to choose where and how I live.
- I can make decisions now about the care I want in my later life.
- I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

2. I know that services are designed around me and my needs

- I feel supported and understood by my GP and get a physical check-up regularly without asking for it.
- There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
- I am treated with dignity and respect whenever I need support from services.
- I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.
- Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.
- My carer can access respite care if and when they want it, along with other services that can help support them in their role.

3. I have support that helps me live my life

- I can choose what support suits me best, so that I don't feel a burden.
- I can access a wide range of options and opportunities for support that suits me and my needs.
- I know how to get this support and I am confident it will help me.
- I have information and support and I can have fun with a network of others, including people in a similar position to me.
- My carer also has their own support network that suits their own needs.

4. I have the knowledge and know-how to get what I need

- It's not a problem getting information and advice, including information about the range of benefits
- I can access to help me afford and cope with living at home.

- I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.
- I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.
- My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

5. I live in an enabling and supportive environment where I feel valued and understood

- I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.
- I am making a contribution which makes me feel valued and valuable.
- My neighbours, friends, family and GP keep in touch and are pleased to see me.
- I am listened to and have my views considered, from the point I was first worried about my memory.
- The importance of helping me to sustain relationships with others is well recognised.
- If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.
- My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

6. I have a sense of belonging and of being a valued part of family, community and civic life

- I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.
- Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.
- My carer and I continue to have the opportunity to develop new interests and new social networks.
- It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

7. I know there is research going on which delivers a better life for me now and hope for the future

- I regularly read and hear about new developments in research.
- I am confident that there is an increasing investment in dementia research in the UK.
- I understand the growing evidence about prevention and risk reduction of dementia.

- As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.
- I believe that research is key to improving the care I'm receiving now.
- I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.
- I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment

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Appendix 3

Quality standard for dementia - NICE

The quality standard for dementia requires that dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.

Number	Quality statements
1	People with dementia receive care from staff appropriately trained in dementia care.
2	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4	People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
5	People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of : <ul style="list-style-type: none">• advance statements• advance decisions to refuse treatment• Lasting Power of Attorney• Preferred Priorities of Care.
6	Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
9	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10	Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

Appendix 4

Quality Outcomes for people with dementia: Building on the work of the National Dementia Strategy – DOH

Outcome	Descriptor	Nice QS	NDS Objective
I was diagnosed early	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.	2,3	1,2
I understand, so I make good decisions and provide for future decision making	Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.	3,5	3,4,5
I am treated with dignity and respect	People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.	1	1,13
I know what I can do to help myself and who else can help me	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.	1, 3, 4, 5	3, 4, 5, 6, 13
Those around me	People living with dementia will	3, 4, 6, 10	3, 4, 5, 7

and looking after me are well supported	feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.		
I can enjoy life	People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.	3, 4	1, 4, 5, 6
I feel part of a community and I'm inspired to give something back	People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research		1, 5, 16
I am confident my end of life wishes will be respected. I can expect a good death	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.	5,9	12,13

Appendix 5

Essex, Southend and Thurrock Dementia Strategy Consultation

About the consultation

'Living well with dementia: A National Dementia Strategy' was published in 2009. Thurrock, Essex and Southend councils have been working together with the Primary Care Trusts and representatives from Voluntary, National Health Services and Independent Provider Organisations to develop an overarching strategy from which local action plans will be produced.

The strategy is a working draft and will be updated following the consultation.

The draft Thurrock easy read strategy sought comments on the following:

- Do you agree with our priorities?
- We have 6 priorities can you please tell us below what order you think we should do these in, with 1 being most important and 6 being least important?
- Do you or someone you care for have dementia?
- If you or someone you know has dementia how easy was it to find information about dementia and the services available?
- Where would you go to get information about dementia and the services that are available?
- What services do you think would be helpful to someone that has dementia and their carers?
- Would you like to be part of a group of people that will help us to plan how we can support people better?

The public consultation began on Monday 27th June 2011 with the consultation running for thirteen weeks and ending on Friday 19th September 2011.

How Thurrock Council engaged with residents?

There were three versions of the consultation document two of which were developed in partnership and the third document of the Essex, Southend and Thurrock Draft Strategy for Dementia 2011-2014 was an easy read of the main summary document produced by Thurrock Adult Social care for local use only. In addition to this Thurrock Adult Social Care ran three public consultation events at various libraries across the borough

Thurrock LINK also held an event that was attended by those who have dementia and there carers.

Putting residents first

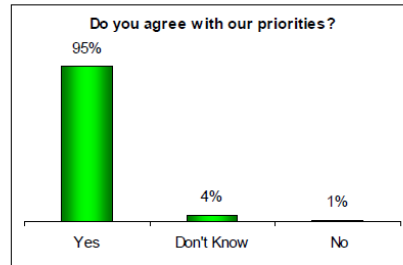
THURROCK COUNCIL
www.thurrock.gov.uk

The Results

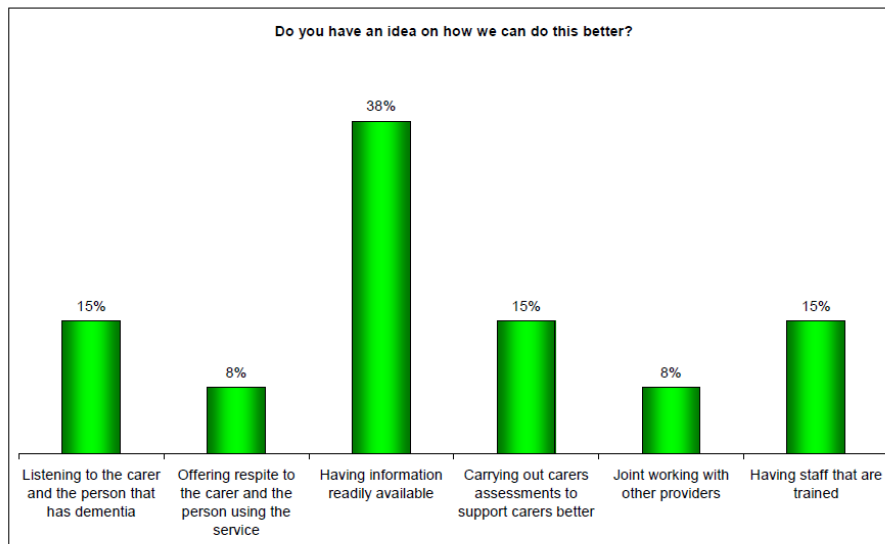
Thurrock received 114 responses all of which were to Thurrock's easy read version.

Essex County Council found 7 themes that encompassed the comments the themes are Carers', service provision, joint working, people, awareness, training and other.

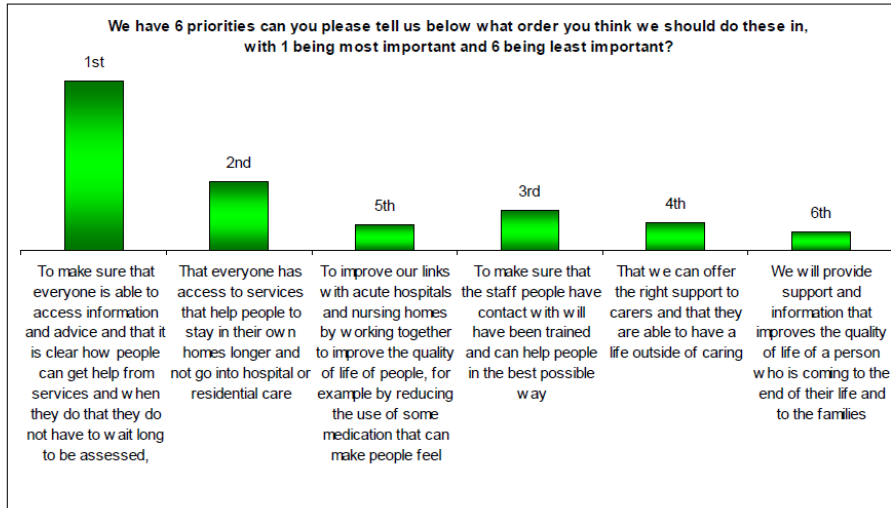
95% of respondents agreed with the six priorities that have been identified for 2011 to 2014. The next question asked if the respondents had an idea on how we could improve on these priorities, we received 31 comments and it was identified that 12 could be used to influence the local action plan and 11 could be used to update the strategy.



Question two asked if the respondent had an idea on how we can do this better; the majority felt that better information and advice was needed in Thurrock.

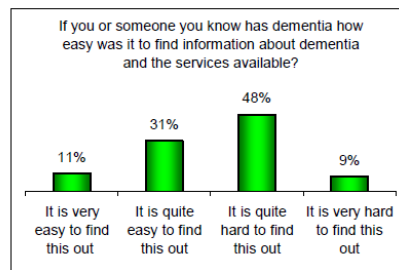


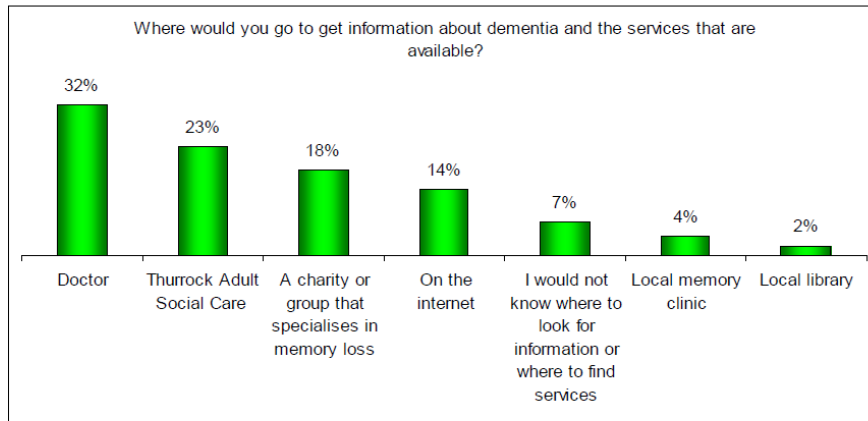
We asked respondents to rank the order in which they felt we should carry out the 6 priorities, with one being the most important and 6 being the least important, 48% said that the priority 'To make sure that everyone is able to access information and advice and that it is clear how people can get help from services and when they do that they do not have to wait long to be assessed, finding out what is wrong with them, getting treatment and support' was the most important.



We asked people how easy it was to find out information about dementia and the services available, 48% of respondents said that they found it difficult to find information and services about dementia. We then asked the respondents where they would go to get information about dementia and the services that are available. We received 97 comments with 32% saying that they would go to their doctor for information about dementia and the services available. 23% would contact Thurrock Adult Social Care, 18% would go to a charity or group that specialises in memory loss, 14% would look on the internet, 7% said they would not know where to look for information or where to

find services, 4% would contact their local memory clinic and 2% would go to their local library.





We also asked people what services they thought would be helpful to someone that has dementia and their carers', we received 68 comments. Using Essex County Council's methodology 28 of these comments could be used for the local action plan and 7 comments could be used to inform the final strategy

