

Staffordshire LINK

Uncharted Waters: Research Into Services For People With Dementia And Their Carers

MAY 2010



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Executive Summary

Helen Kara from We Research It Ltd, and Debs Sambor from Mercian Research Associates, were commissioned by Staffordshire LINK in March 2010 to investigate dementia services across the county. We spoke to people from the north and south of the county: eight people with dementia, 30 carers, 11 professionals, and one member of Staffordshire LINK who is also a carer. We also read and analysed numerous national and local documents.

We have called our report 'Uncharted Waters' because that is where it seems we are in relation to dementia: as a society, as service providers, as people with dementia and as their carers. None of us know exactly where we are going, or what the journey will be like along the way. However, we now have some information to guide us: the national dementia strategy, other national and local strategies, plans and consultations, and the lived experiences of people with dementia and their carers, as well as this research.

Our findings are laid out in the following pages, and we have made ten recommendations on the basis of these findings. We recommend that Staffordshire LINK should:

1. Work to ensure that support for people with dementia and their carers is focused around times of transition.
2. Focus efforts on the ten major gaps in services identified by the research.
3. Work to overcome the five main barriers to accessing services which were identified by this research.
4. Gather and monitor information about pressure on existing services.
5. Make use of existing evidence, or evidence collected by partners, where possible.
6. Use the findings of this research to influence decision-making about where to focus consultation efforts.
7. Use a range of techniques, as appropriate, to involve people with dementia in the consultation process.
8. Find, and use ways to consult, carers and people with dementia who don't go to carers' or other groups.
9. Help to publicise work that is being done in the county to improve and develop dementia services, as well as identifying further need for services.
10. Create an action plan with SMART objectives for the implementation of the above nine recommendations.

These recommendations, and the rationale for each of them, are discussed in more detail on pages 4–7 of this report. We know that our report is a very small piece in a very large jigsaw, but we hope it will make a positive difference for people in Staffordshire who are living with dementia and its consequences.

Introduction and Methodology

Helen Kara from We Research It Ltd, and Debs Sambor from Mercian Research Associates, were commissioned by Staffordshire LINK in March 2010 to investigate dementia services across the county. Staffordshire LINK wanted “to better understand current issues in relation to dementia services across the Staffordshire area and to progress a project that would enable a patient and public viewpoint to influence how services are planned, commissioned and delivered in the future.” In particular, Staffordshire LINK wanted the researchers to:

- Identify existing information that identifies local health needs in relation to dementia. In particular seek out any information regarding variations in need across different geographic areas or sectors of the population and different stages of the disease
- Identify existing information which identifies patient/public experience or concerns in relation to dementia services in Staffordshire, including barriers in access to services or gaps in service
- Examine any information that identifies performance or progress in Staffordshire against national standards or best practice
- Seek the views of local NHS commissioners and VCS organisations and groups on the key issues in Staffordshire in relation to dementia
- Engage with the wider community where appropriate to understand specific issues or test known areas of concern in relation to dementia services in Staffordshire
- Identify any plans for investment, efficiency, service development or reconfiguration
- Report on findings and propose where the LINK might best focus its attention in seeking the involvement of local people in influencing services developments and/or highlighting areas for improvement

Helen and Debs spoke to people with dementia and their carers at one group and one dementia café in the south of the county (Burton and Burntwood), and one day centre and one dementia café in the north of the county (both in Newcastle). In total, they spoke to eight people with dementia and 30 carers. The questions they used are in appendix 1.

They also spoke to eleven professionals in a range of roles across the county (see appendix 2 for details) and one member of Staffordshire LINK who is also a carer. Nine professionals participated in semi-structured interviews by telephone, and one – at the interviewee’s request – face to face. (Interview questions are in appendix 3.) The eleventh professional participated in a short conversation by telephone, and the member of Staffordshire LINK participated in a face-to-face interview.

During the research process, two of the professionals disclosed that they are also carers for people with dementia, as is one of the researchers.

Several participants provided relevant documents, and other relevant local and national documents were sourced from the Internet. The researchers read and analysed these documents (which are listed in appendix 4). Because of the number of documents collected, the detailed analysis is quite long, so analytic summaries have been provided to Staffordshire LINK separately from this report.

Data collected directly from people in the county was coded and analysed using computer software (NVivo).

All analysed data, from both documents and interviews, has been used in the preparation of this report and its recommendations. The next section of the report discusses the rationale for each of the recommendations. The following section gives full details of the research findings, with evidence, for those who want a deeper understanding of these. This findings section uses the structure provided by Staffordshire LINK in their brief for the research, as set out in the bullet-pointed list on the previous page, to demonstrate how each part of the brief has been fulfilled in the research process. In the findings section, text in bold at the start of each sub-section provides a reminder of the point from the brief which is being addressed in that sub-section. Supporting information is contained in appendices.

Recommendations and Discussion

We were asked by Staffordshire LINK to help it 'better understand current issues in relation to dementia services across the Staffordshire area' and to 'enable a patient and public viewpoint to influence how services are planned, commissioned and delivered in the future'. On the basis of the findings from this research, we have made ten recommendations for Staffordshire LINK:

Recommendation 1: work to ensure that support for people with dementia and their carers is focused around times of transition.

Times of transition include:

- At and immediately after diagnosis
- Whenever the behaviour of the person with dementia changes
- When paid care is first used
- When any respite service is first used
- When the person with dementia develops other health problems
- When the carer develops other health problems
- When the person with dementia goes into hospital, and during any recuperative period
- When the carer goes into hospital, and during any recuperative period
- When the person with dementia goes into residential care
- When the person with dementia dies, and thereafter

These are the times when carers and people with dementia need easy access to responsive support. Between these times, there may be periods of years when families can manage perfectly well with little or no support. At times of transition, crises can develop quickly if support is not available and effective. A quick tailored intervention can prevent the escalation of a situation into a stressful and costly hospital or care home admission.

Recommendation 2: focus efforts on the ten major gaps in services identified by the research.

This research identified ten major gaps in services, some of which are being addressed through existing work. These gaps are:

1. Little or no support at the times of transition identified above
2. An almost complete lack of services addressing the needs of younger people with dementia, who have different needs from the over 65s (there are an estimated 240 people in Staffordshire with early-onset dementia, and this group are recognised by the national strategy as in need of differently tailored services from those whose dementia develops later in life)
3. An almost complete lack of services addressing the needs of older carers – those over the age of 80 – who are increasing in number

4. No named key workers for people with dementia and their carers (even though this is defined as best practice both nationally and locally, and has been acknowledged and promised at “Your Voice” conferences each year for the past three years)
5. Usually no regular assessments of the needs of people with dementia, or their carers (although both of these are mentioned in the national strategy as essential – some work is being done locally on assessments for people with dementia, but apparently little on assessments for carers)
6. Lack of access to re-enablement services for people with dementia
7. Very little extra support for carers who develop health problems of their own
8. Very poor service in many hospital settings for people with dementia and, by extension, their carers (appendix 7 shows that this is beginning to be addressed through the appointment of specialist hospital staff in South and North Staffordshire, and by training of existing hospital staff in North Staffordshire)
9. No access to Admiral nurses – the nearest one is in Worcester
10. No effective service provision outside office hours, even to cater for emergencies – the burden here falls on GPs (there is talk of a helpline through Staffordshire Cares, but nothing concrete)

Recommendation 3: work to overcome the five main barriers to accessing services which were identified by this research.

The five main barriers identified by this research are:

1. The stigma associated with dementia
2. Lack of awareness of dementia and of services
3. Funding constraints and continual service reconfiguration
4. Physical barriers to accessing services
5. Barriers created by some GPs

Talking about dementia, and increasing awareness of the illness and of services available for those affected, will help to overcome the stigma.

In the current economic climate, funding constraints are inevitable. Some service reconfiguration is necessary to create efficiencies and free up funds for much-needed extra services. However, service reconfiguration that adversely affects services provided directly to people with dementia and their carers should be avoided as far as possible, because of this group's particular need for continuity and familiarity.

Where physical barriers to accessing services exist, generally service providers were aware of these barriers and taking steps to manage or remove them.

A few GPs in Staffordshire are demonstrating excellent and even innovative practice with people with dementia and their carers. However, many carers report lack of information and support from GPs at and after diagnosis. It would also be interesting to know the extent of GPs' role in the large number

of undiagnosed cases of dementia in the county. This is not particular to Staffordshire. Research cited in the national dementia strategy describes it as a national problem, saying:

“A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources.” (p. 36)

Professionals in Staffordshire report a lack of awareness of dementia services on the part of GPs, and GPs’ unwillingness to share their carers’ registers. We would hope that the training for GPs which is being undertaken by South Staffs PCT will help to overcome the difficulties reported by carers and professionals in that area, as well as making those GPs’ complex and difficult working lives a little easier.

Recommendation 4: gather and monitor information about pressure on existing services.

This research found that existing services are under increasing pressure, often with long waiting lists. The scope of this research did not allow for a comprehensive assessment of pressure on existing services, but the findings indicated the presence of a serious and growing problem which would merit further enquiry.

Recommendation 5: make use of existing evidence, or evidence collected by partners, where possible.

Consulting people with dementia and their carers can be challenging. Some people with dementia find communication difficult, so extra time and special techniques may be needed to consult effectively with them. Carers may be overwhelmed by the demands of their role and/or unable or unwilling to express their needs in front of the person they care for. They may also have little or no time away from their caring role, and may be reluctant to use any free time they do have for participating in consultation.

These factors should not be used as an excuse to avoid consulting people with dementia and their carers. However, any consultation must be approached with sensitivity and awareness that people with dementia and their carers may be more prone to ‘consultation fatigue’ than other sectors of the population. People with dementia and their carers should only be consulted when necessary, not tokenistically, to tick a box, or in work which has been or is being duplicated elsewhere in the district or county.

Recommendation 6: use the findings of this research to influence decision-making about where to focus consultation efforts.

There are already sizeable bodies of evidence on a number of key issues, such as the need for better support for people with dementia in hospitals, and

the need for more support for those caring for people with dementia. Rather than collecting further evidence on such issues, Staffordshire LINK should focus on monitoring services to assess levels of improvement, using the elements of best practice identified in this report for guidance.

Recommendation 7: use a range of techniques, as appropriate, to involve people with dementia in the consultation process.

Some people with dementia are able to take part in a conversation, interview or focus group, or complete a questionnaire. Others find conventional communication more difficult, and for these people, pictorial or symbolic methods, or tools such as 'Talking Mats', may be more appropriate. People with dementia should always be consulted in surroundings which are familiar to them, by non-judgemental people who are informally dressed, and without being rushed.

Recommendation 8: find, and use ways to consult, carers and people with dementia who don't go to carers' or other groups or services.

For this research, service users were consulted at existing groups and services for carers and people with dementia. This is a valid way of consulting people, and was endorsed by those consulted for this research. However, there are a large number of carers and people with dementia who do not use existing groups and services, whether because they do not choose to, or because the existing services are full, or for some other reason. The views of those who do not currently use services, whatever the reason, should also be included, as they may give quite a different picture. It should be possible to make contact with such people through specialist staff and organisations such as dementia navigators/advisers/support workers and carers' associations.

Recommendation 9: help to publicise work that is being done in the county to improve and develop dementia services, as well as identifying further need for services.

Of course it is part of the role of Staffordshire LINK to identify further need for services. However, it would be reassuring for people with dementia and their carers, and might help to remedy consultation fatigue, if as part of every consultation exercise Staffordshire LINK helped to raise awareness of the considerable amount of work that is being done at county, PCT and district level to improve and develop dementia services.

Recommendation 10: create an action plan with SMART objectives for the implementation of the above nine recommendations.

This will enable the recommendations to be followed through, and provide lines of accountability for Staffordshire LINK and its constituents.

Findings: Local Health Needs

Identify existing information that identifies local health needs in relation to dementia. In particular seek out any information regarding variations in need across different geographic areas or sectors of the population and different stages of the disease

Existing information says very little about local health needs in relation to dementia. It does map and predict the prevalence of dementia, and this is set out below. Other health needs in relation to dementia were discussed by research participants, which yielded four main findings; these are reviewed in detail below.

Current and Future Prevalence of Dementia: Predictions

In August 2009, Staffordshire Joint Strategic Needs Assessment made a draft estimate of current and future prevalence of dementia in Staffordshire. They concluded that at present, around 240 people in Staffordshire aged 30–64 are estimated to have early onset dementia, with numbers in this age group predicted to remain similar in future years.

Table 1: People aged 30–64 predicted to have early onset dementia in Staffordshire

	2008	2010	2015	2020	2025
Males	140	139	137	144	149
Females	97	97	96	100	102
Persons	237	236	233	244	251

Note: Figures may not add due to rounding

Table 2: People aged 30–64 predicted to have early onset dementia by district

	2008	2010	2015	2020	2025
Cannock Chase	25	26	26	27	29
East Staffordshire	29	30	31	33	35
Lichfield	29	29	28	30	31
Newcastle	34	34	32	34	35
South Staffordshire	32	32	32	32	32
Stafford	36	36	36	36	37
Staffs Moorlands	30	29	29	30	30
Tamworth	20	21	20	21	20
Staffordshire	237	236	233	244	251
England	13,022	13,188	13,358	14,330	14,929

Note: Figures may not add due to rounding

Source: Projecting Adult Needs and Service Information (PANSI)

The same study also reports on dementia prevalence rates in people aged 65 and over. This shows that in Staffordshire, 3,400 men and 6,400 women aged 65 and over were estimated to have dementia in 2008. By 2015 these numbers are expected to increase to 4,400 men and 7,500 women.

Comparison with expected numbers of people with dementia show that numbers on GP disease registers significantly under-record the prevalence of dementia in the county.

Table 3: People aged 65 and over predicted to have dementia in Staffordshire

	2008	2010	2015	2020	2025
Men					
65–69	324	350	411	365	383
70–74	530	567	660	781	701
75–79	638	663	801	949	1,137
80–84	826	877	1,020	1,285	1,550
85 and over	1,044	1,162	1,537	2,029	2,738
65 and over	3,362	3,619	4,429	5,409	6,509
Women					
65–69	224	245	288	257	273
70–74	446	473	559	660	593
75–79	1,034	1,040	1,177	1,398	1,658
80–84	1,623	1,676	1,822	2,115	2,527
85 and over	3,024	3,175	3,679	4,284	5,267
65 and over	6,351	6,609	7,525	8,713	10,317
People					
65–69	548	595	699	622	656
70–74	976	1,040	1,219	1,441	1,294
75–79	1,672	1,703	1,978	2,347	2,795
80–84	2,449	2,553	2,842	3,400	4,077
85 and over	4,068	4,337	5,216	6,313	8,005
65 and over	9,712	10,228	11,954	14,122	16,826

Note: Figures may not add due to rounding

Source: Projecting Older People Population Information (POPPI)

Table 4: People aged 65 and over predicted to have dementia by local authority

	2008	2010	2015	2020	2025
Cannock Chase	950	1,026	1,218	1,446	1,759
East Staffordshire	1,223	1,266	1,443	1,685	2,058
Lichfield	1,177	1,252	1,486	1,828	2,202
Newcastle	1,561	1,615	1,795	2,033	2,290
South Staffordshire	1,362	1,452	1,715	2,084	2,504

Stafford	1,597	1,690	1,971	2,321	2,778
Staffs Moorlands	1,258	1,318	1,509	1,781	2,110
Tamworth	617	638	781	956	1,172
Staffordshire	9,712	10,228	11,954	14,122	16,826
England	591,284	611,205	678,461	770,817	893,632

Note: Figures may not add due to rounding

Source: Projecting Older People Population Information (POPPI)

In March 2010, the JCU updated some of their projections for the county and its districts, extended them to 2030, and calculated the percentage changes¹. They estimated the total numbers of people aged 65+ with dementia, and of these, the numbers with very high needs (i.e. severe cognitive impairment and functional disability needs).

Table 5: County estimated total numbers

	2010	2015	2020	2025	2030
Others with dementia	5,910	6,870	8,110	9,520	11,080
Very high needs	4,320	5,090	6,020	7,320	8,610
All with dementia	10,230	11,960	14,130	16,840	19,690

Table 6: County % change from 2010

	2015	2020	2025	2030
Others with dementia	16%	37%	61%	87%
Very high needs	18%	39%	69%	99%
All with dementia	17%	38%	65%	92%

Table 7: District/borough estimated total numbers

	2010	2015	2020	2030
Cannock Chase	1,030	1,220	1,450	2,070
East Staffordshire	1,270	1,440	1,690	2,410
Lichfield	1,250	1,490	1,830	2,570
Newcastle-under-Lyme	1,620	1,800	2,040	2,660
South Staffordshire	1,450	1,720	2,090	2,890
Stafford	1,690	1,970	2,320	3,240
Staffordshire Moorlands	1,320	1,510	1,780	2,480
Tamworth	640	780	960	1,420

¹ Tables 5–9, and tables in appendix 5, taken from *Information For Service Planning*, JCU 2010

Table 8: District/borough % change from 2010

	2015	2020	2030
Cannock Chase	18%	41%	101%
East Staffordshire	13%	33%	90%
Lichfield	19%	46%	106%
Newcastle-under-Lyme	11%	26%	64%
South Staffordshire	19%	44%	99%
Stafford	17%	37%	92%
Staffordshire Moorlands	14%	35%	88%
Tamworth	22%	50%	122%

It is interesting that although Tamworth has the lowest projected numbers, it has the highest projected percentage change. Conversely, Newcastle-under-Lyme has the third highest total numbers, but the lowest projected percentage change. Stafford, with the highest total numbers, has a mid-range projected percentage change.

It is also interesting to compare these figures with the total population projections for over 65s in the county and districts (appendix 5). The comparison shows that in every district, over the next 20 years, dementia is expected to rise much faster than the population itself.

Table 9: District/borough and county comparison between projected population increases and projected dementia for 2030 (over 65s only in both cases)

	2030 projected population	2030 projected dementia
Cannock Chase	61%	101%
East Staffordshire	63%	90%
Lichfield	54%	106%
Newcastle-under-Lyme	41%	64%
South Staffordshire	52%	99%
Stafford	53%	92%
Staffordshire Moorlands	53%	88%
Tamworth	75%	122%
Staffordshire as a whole	54%	92%

Local Health Needs

This research produced four main findings around local health needs:

1. the health service is not consistent in diagnosing dementia and providing suitable post-diagnosis support
2. pressure on existing services is growing, which needs addressing urgently
3. the re-enablement of people with dementia is not the high priority it should be
4. people with dementia who develop other physical or mental health problems are often poorly catered for

The issue of diagnosis and post-diagnosis support is also reviewed later in this report, primarily from the points of view of people with dementia and their carers. It is reviewed here from the points of view of people who were interviewed in their professional roles.

Diagnosis and Post-Diagnosis Support

GPs are the gateway to diagnosis but, as discussed above, the prevalence of dementia in the county is significantly under-recorded by GPs. This reflects the national picture as set out in the national dementia strategy. Some GPs in Staffordshire are demonstrating excellent practice, and this is likely to increase as more GPs are trained in dementia awareness, but at present it is quite rare.

GPs are the gateway to diagnosis, they're varied, but it's safe to say GPs have a patchy knowledge, their attitude is dismissive and patronising, and it's unusual to get a GP that is knowledgeable, sympathetic and will refer for diagnosis and investigation. I've had them say, 'it is dementia, what do you expect?' I've had a GP say, within two weeks of me visiting him to give information on local services, I then spoke to a carer who had visited the GP who had said there's no support services in this area. (professional)

In this area, when there's a clear memory loss issue and the GP refers to the memory clinic, that's the initial outpatient clinic, 60% are told at the end of the consultation, 'yes you have dementia illness' and that is it. They're told to get power of attorney, and leave. One lady, that was her experience, told there was nothing she can do, it's a one way street, get in touch again when things get worse. It was devastating. You wouldn't be told you'd got AIDS etc without post-diagnosis support. (professional)

Some of this is because GPs are general practitioners and rely on scarce specialist resources for support.

In terms of needs we have a psycho-geriatrician, our psychiatry services are zonal, she covers quite a large patch with 1 CPN attached to her who does outreach and clinics, they do a memory clinic and outpatient services for patients with dementia... the medical psycho-geriatrician role is very limited in our area, i.e. we've only got one and she covers a huge patch, it's not a

responsive service, I don't think it's her fault, she's got a huge patch and enormous workload, but some kind of access into medical psycho-geriatric advice in a more timely way would be very useful. Her clinics have got long waits. (professional)

Early diagnosis and appropriate support is essential for people with dementia and their carers, and also saves money for public services.

If someone with dementia isn't picked up until their symptoms are so bad, they've probably got cognitive impairment so they can't make any choice about their care, end of life care, etc. We need to pick up the diagnosis earlier and support them through quite a devastating diagnosis. The pathway of the disease can go on for many many years, they might be physically and mentally quite well for a number of years, they need to get the most out of those years. We need to give the families that opportunity, which is why we've concentrated on primary care, the dementia adviser can pick it up early and work with the family to plan a whole range of things for the future. If we can put in support where it's needed, we can keep people out of hospitals and care homes for much longer. (professional)

Of course some people don't want a diagnosis, or choose to keep their diagnosis secret.

She's never told her husband she has dementia and doesn't want to, the strain on her is phenomenal. (professional)

Some may not want a diagnosis, and you have to respect their wishes, and others might not want services until they need them, we have to give them that option as well, but we have to make sure that those who want support get support when they need it through the whole pathway. (professional)

In such cases, people's rights must be respected, but they are likely to be in a very small minority, and will certainly not account for the levels of under-recording seen both in the county and nationally.

Pressure on Existing Services

Dementia cafés have high levels of attendance, often catering for 40 to 50 people. Day care is oversubscribed in some areas of the county with long waiting lists. In other areas it is difficult to find residential places for people with challenging behaviour or complex needs. There are long waits for psycho-geriatric clinics. Dementia cafés and dementia advisers are reliant on the support of volunteers to meet the needs of the local population. Social care and health are so overloaded that it's hard for them to respond to requests for help. This research has not produced a comprehensive assessment of pressure on existing services, as this was only one element of a multi-faceted investigation, but the findings are indicative of a wider, deeper problem which might merit further enquiry.

We've had a waiting list for the past four years, it's grown from a couple to 35. In the last six to twelve months, because of the waiting list we have to score people. I don't agree with it. We're finding people are coming and not staying long. We are trying to support a sinking ship. If care had gone in at the assessment point, maybe things would have been able to continue. Previously we had people come earlier, one woman's been coming for 13 years so we've seen her through all the stages. If we get people too late we can't do anything. The criteria for assessment is strict and if they're not picked up early, they're not getting help. In some cases people have been waiting months for a social worker to go out and that's not working. (professional)

It's fair to say if you spoke to any families looking for placements it's very difficult to place people who are challenging or have very complex needs, they are impossible to place locally, there's no units, the nearest is in Burton from Tamworth. There's a definite gap in that sort of end of the service, there's lots of residential provision and a fair amount of day care in Tamworth, but when behaviour is more of an issue, there's not so much provision. (professional)

Re-enablement

Re-enablement is essential for people with dementia, but it can also be challenging and time-consuming because of the nature of the condition. It needs to be a high priority.

It's a life-changing long-term condition and so obviously there are great changes in people's lives and it's getting in there and saying 'yes but there is a re-enablement model, we won't get people back driving cars or back into work they really loved, but we can get to know people and their social history and support them to create well-being and maintain mental stability.' It's when the well-being goes out of the window that things start rocking and people get worse. People can still be supported in terms of well-being at the latest stages of profound dementia. (professional)

Gaps in service, I suppose the main one I would identify is re-enablement for people with dementia. We still sometimes come across the prejudice that people with dementia can't learn new tricks so there isn't any point doing re-enablement with people with dementia. It's different, we're not wanting people to learn new tricks, we're wanting them to remember the old ones. So people who have both dementia and a physical problem, I think we've certainly had anecdotal evidence so I can't say how widespread it is, are not getting the physical issues addressed because everything is put at the door of the dementia or they're not seen as being helpable because they can't respond to treatment, or they're difficult. That communication of sitting alongside someone and waiting for them to say something that gives you a hook is very time-consuming, and I think sometimes the pace of work we have to do, because of the volume, means that it's quite difficult to take the length of time it takes to communicate and to hear and understand what people with dementia are saying and the context for what they're saying. If we knew them

well enough, and could be where they are, what they are saying would make sense, but we don't often know that context. (professional)

My main interest is I'm trying to develop my memory because I can walk out the door and not remember the way back again. Here we reminisce about old films etcetera, that helps my memory... Anything to stimulate the memory. Quite a few here have got memory problems, the staff ask quiz questions, if you remember the words of songs and things like that, it gets the memory working. If you have ideas for encouraging that, it would be helpful, because it's very important. (person with dementia)

Other Health Problems

When a person with dementia develops other physical or mental health problems, this puts enormous pressure on the person themselves and on their carer(s). Extra support is needed at these times, particularly if the person with dementia has to be admitted to hospital. This is discussed in more detail on pages 28–29 below.

Findings: People's Experience and Concerns

Identify existing information which identifies patient/public experience or concerns in relation to dementia services in Staffordshire, including barriers in access to services or gaps in service

Experience and Concerns

The great majority of people with dementia want to continue living in the community, even if they live alone. Most of those caring for people with dementia want the person they care for to stay with them in the community for as long as possible. And professionals want to help people stay in the community, partly because they know this is what people usually want, and partly because it's cheaper than the alternatives.

However, for people with dementia to live happily in the community and be effectively cared for by people in their own families, without adversely affecting the health of those carers, support is needed. Often not a great deal of support: in many situations a word of advice is enough, a simple tip on how to deal with a new problem. In other situations assistive technology can help, and again, this can be as simple as a special bath or sink plug which prevents water overflowing if a tap is left running. A day a week of respite can be a lifeline to a carer, and good day care provision is also appreciated by people with dementia.

Most carers don't see their role as a job; it is something they do out of love for the person with dementia. Yet it is a demanding role, 24 hours a day, 7 days a week, often with new challenges to face as the person's behaviour changes or new health problems develop for the person with dementia or for their carer.

This research has shown that practical and emotional support for people with dementia and their carers is particularly needed at times of transition. These include:

- At and immediately after diagnosis

The diagnosis means a complete change in life styles and expectations of both the patient and carer or carers, whether they be spouse, daughter and son etc. (carer)

- Whenever the behaviour of the person with dementia changes

These training sessions, it was things like about the diagnosis, what is dementia and the different kinds of dementia, how to deal with unexpected behaviour and new patterns of behaviour. (professional)

- When paid care is first used

During the handover period of family caring and then to paid carer, sometimes there's not sufficient dialogue. Assessments will be done, but the person who knows them most i.e. the family carer doesn't always get the opportunity to input, so it's about are they recognised and valued. (professional)

- When any respite service is first used

All carers feel guilty, the first time she went for respite I felt terrible, one of the nurses said 'don't go in, just ring up,' I still feel guilty even though she's happy there. (carer)

- When the person with dementia develops other health problems

My mum's been having these mini-strokes, since Christmas she's had a lot and she keeps falling, I've gone from my mum being totally independent in four months to where she can't do anything for herself. This is only my second time at this group, nobody gave me any advice before I came here, I don't know where to go or what to do. (carer)

- When the carer develops other health problems

I had five and a half months last year with severe back pain and that opened my eyes. (carer)

I think if you've got health problems, you've always got a problem trying to be a carer. Sometimes if you've got problems yourself then you struggle, you can get help morning and night and then you're left alone to cope as best you can and you're not always up to it. (carer)

- When the person with dementia goes into hospital, and during any recuperative period

Nobody at the hospital gave me any information. (carer)

We have a routine, I'm hoping they will let me have her back home. (carer)

- When the carer goes into hospital, and during any recuperative period

The respite thing, we are entitled to six weeks in each year. What happens if someone's had their time and the carer has to go into hospital, what happens then? When I spoke to Approach they didn't know, it needs to be made clear to people what happens. Perhaps people aren't aware, because quite frankly respite is to give a rest, if you've taken that time up and something goes wrong, you're up the creek. If you don't take respite for a year it doesn't carry over. Social services told me this, if I wanted him to stop longer I'd got to pay the £500 a week, some people maybe their family can help out. You could be ill or taken sick, they should be able to go to respite. If it's an emergency they should be taken on, no question. Being in hospital is not respite for the person caring. (carer)

I'm a carer, if someone's been in hospital it's a month to six weeks for social services. If the carer's in hospital they don't get the care unless you put your hand in your pocket. You can't care for them if you've been in hospital. (carer)

- When the person with dementia goes into residential care

I just put my wife in care, four weeks ago, to be quite honest they gave me no help at all... They've never even rung up, my wife's been in care for a month, it's very hard to leave her after 30-odd years, the social services have never rung me up to see how I'm coping. (carer)

- When the person with dementia dies, and thereafter

The other thing we do, I think it's the only group in the county, we have an ex-carers group. We found that people's needs change: as the person they care for goes into care or passes away, they have no support, they may have lost their friends etc. They meet once a month, it's more of a social group, or a catalyst because they've all got something in common and they go off and do things. (professional)

It's over three years since the person I was looking after with dementia has died. I have been a carer nearly all my life. (carer)

Gaps in Services

In Staffordshire, there are numerous gaps in services for people with dementia and their carers, at county, district and local level: too many for this research to identify all of them. However, we did identify ten major gaps, which are:

1. Little or no support at the times of transition identified above
2. An almost complete lack of services addressing the needs of younger people with dementia, who have different needs from the over 65s
3. An almost complete lack of services addressing the needs of older carers – those over the age of 80 – who are increasing in number
4. No named key workers for people with dementia and their carers
5. Usually no regular assessments of the needs of people with dementia, or their carers
6. Lack of access to re-enablement services for people with dementia
7. Very little extra support for carers who develop health problems of their own
8. Very poor service in many hospital settings for people with dementia and, by extension, their carers
9. No access to Admiral nurses – the nearest one is in Worcester
10. No effective service provision outside office hours, even to cater for emergencies – the burden here falls on GPs

Barriers to Accessing Services

We also identified five main barriers to accessing existing services. The stigma associated with dementia was identified as a barrier by professionals, carers and people with dementia.

Dementia in all of its forms is “stigmatic” illness. The population in general is frightened of it and its impact on life... we do not want to acknowledge we or someone near to us has dementia. (carer)

We’ve got to de-stigmatise, and by doing that we can then support people. It’s exactly the same as the cancer issue 25 years ago, we didn’t talk about it and people suffered in silence, look at the way we now support people with cancer and the whole society change, we’ve got to make that change with age-related dementias. (professional)

Lack of awareness of dementia and of services is also seen as a barrier.

Carers tend to get on with it and see it as a responsibility, because it’s a husband or wife or family member, and lack of awareness of the fact that there is help, and that dementia is a treatable condition, is the biggest barrier to accessing services. (professional)

Funding constraints and continual service reconfiguration also create barriers.

Because of structures and funding issues and the economic climate, lots of things have been put on hold, difficult decisions will have to be made. (professional)

Social care and health are going through their third restructure and another one is due. It makes setting up information and referrals difficult. (professional)

There are also still physical barriers to accessing services.

Our GP, the access is very good but in the surgery they put up doors that open inside, they should have sliding doors for wheelchairs. The people there, staff and patients, are happy to hold doors open for you. (carer)

We’ve got to get out of this building, it’s inappropriate, too small, my client group can’t get to me, up the stairs, I hate that, people can’t just wander in my door and have a chat. (professional)

Carers from two of the four groups we attended, and four of the professionals we spoke to, thought GPs created barriers to accessing other services. For carers, lack of information at diagnosis was the main problem, while for professionals, GPs’ lack of awareness of services and unwillingness to share their carers’ registers can also cause difficulties.

I know when I went to see my GP, when I'd realised what unusual things my husband was doing, and he said 'thank you for coming, you've clarified the position for me, and I have to tell you your life will never be the same again.' I walked out and looked around me and wondered why everyone else was normal, I didn't feel normal at all. (carer)

The GPs did nothing, the GP will do anything you ask him for but won't spark it off, didn't tell me about CASS² or anything. I took the leaflets into the GP's surgery, we all think that's where it should come from. (carer)

One person with dementia praised their GP, saying, 'Our GP is very good indeed, I'm pleased with the medical care.' There was also some understanding from carers and professionals that GPs have a complex and demanding role, and there is evidence that changes are being made. For example, there was a training event for GPs in the Tamworth, Burntwood and Lichfield areas in February 2009, attended by 60 people.

CPNs are usually very adept at picking up changes in behaviour whereas GPs are GPs, that's their specialism not mental illness. (carer)

In some GP surgeries there are carers' notice boards providing helpful information, and some surgeries have a member of staff with responsibility for carers. (carer)

I think we should applaud that South Staffs PCT have done this right, they're using the money for training for GPs and clinical staff, and setting up memory clinics in primary care not secondary care which I think is very very positive, and support workers. All those key issues about early diagnosis, offering support and treatment not just leaving people with a diagnosis and nothing else, are being addressed through dementia strategy funding. I think it's really really good, and leaving GPs able to offer support, often it's not lack of willingness, they just don't know. (professional)

One GP in the South Staffs PCT area is championing community-based dementia services.

He did a mini-pilot and was able to show savings on his secondary care mental health budget, and also – and more importantly – feels that he's been giving his patients a much better service because they're getting care closer to home in a GP practice, which helps remove a lot of the stigma associated with mental health and dementia. It's his model we're trying to roll out in south Staffs, the pilot has been flagged as best practice, he was a speaker in the national dementia conference last November, it is very innovative. (professional)

Praise for Services

² Carers' Association of South Staffordshire – third sector organisation providing support for carers

Some services were praised, particularly day care services, dementia cafés, carers' support groups, CASS, CPNs, residential respite services and specialised transport services. GPs and social services were praised by some people, while others were critical.

I'm more than satisfied with social services, when I've had trouble, I can't find anything to fault. They've given me crutches or no matter what I want, helped in getting beds and seats raised, and for the toilet and to make everything comfortable, it all helps. (person with dementia)

I've been in hospital so my husband went into respite, the service I was more than satisfied with. (carer)

It's nice here, it saves the wife going round and doing everything. (person with dementia)

You don't feel so on your own, it feels like you're on your own when you're in your own house and here it's more relaxed. (carer)

Where there is criticism of services, it is often about the organisation or availability of the services rather than their delivery.

Politically people think of a dementia café, there's a feeling that this is the solution to being a dementia carer. Once a fortnight they are not solving the 24/7 role, although they do provide high quality information and support and the sense of not being alone. (professional) (NB: in fact dementia cafés are held monthly, not fortnightly)

We're not given the emergency number to ring up at social care, you have to find it, there's supposed to be someone on duty all the time. I have found my way round that because I've got enough contacts, I ring names not numbers and I get action, this is what we need. I had to go into hospital for a day, within half an hour, one phone call, I had it all organised for my wife, if I'd gone through a social worker it might have taken four weeks. (carer)

I've moaned at my carers, the care is good, but they come at different times and you can't get them regular. I've had them regular for a few weeks in the morning but then you get a different one at night. Again it's the caring people, they just send whoever they've got. (carer)

Findings: Best Practice

Examine any information that identifies performance or progress in Staffordshire against national standards or best practice

This research did not uncover any information that identifies local performance or progress against national standards or best practice. However, we did identify elements of best practice, both nationally and locally, which may form a useful benchmark for future assessment of local performance and progress.

In April 2007, the National Care Forum (NCF) published a statement of best practice in person-centred dementia care. The statement was prepared by the NCF Older People and Dementia Care Committee to specify indicators of quality in relation to person-centred dementia care services.

The key indicators of best practice that they defined were:

- A full assessment is undertaken prior to a service being provided
- Evaluation and reassessment is ongoing
- All relevant documentation used by the organisation demonstrates that the individual is fully involved
- Cultural needs are appropriately considered
- Well-being for the individual is actively promoted
- The language used will be acceptable to the person receiving care
- Care plans are used as communication tools – evaluation is meaningless in the absence of well documented care
- A key worker system matches individuals and staff
- Relatives (and significant others) feel involved and supported.

The Department of Health Implementation Plan for the National Dementia Strategy, published in July 2009, identifies best practice in some specific areas of work relating to people with dementia and their carers and covering most of the objectives of the Strategy. Examples of these areas of work include:

- Assessing dementia
- Awareness of carers' needs
- Importance of communication skills
- Offering choices around the outcomes that have been shown to be particularly important to older people with dementia, which include: personal safety, social contact, opportunities to be active, having control over everyday life, and feeling valued and respected
- Providing appropriate services for people with dementia from minority ethnic groups
- Information for paid carers
- Dementia care in sheltered housing

- The care of adults who are malnourished, or at risk of malnutrition, in a hospital, care home or community setting
- Assistive technology
- Staff training
- Integrating health and social care services

Best practice identified by local people for this research includes:

- Mental wellbeing clinics, like those operating in Stoke-on-Trent, run by a community psychiatric nurse, and ideally offering regular mental wellness checks for all to facilitate early diagnosis of dementia
- Memory clinics, based in the community, with a dementia adviser to support each family from before a formal diagnosis is made, and a full care plan for each person with dementia, reviewed annually
- A named key worker for every person with dementia and their carers
- Regular needs assessments for every person with dementia and their main carer
- Information about carers and support for carers to be readily available in all GPs' surgeries
- Dementia support workers/advisers/navigators throughout the county
- Carers' support throughout the county
- Dementia cafés throughout the county
- Providing stimulating activities for people with dementia, both within and outside the family
- Access to re-enablement services for all people with dementia
- Helping people with dementia to continue contributing to society for as long as possible
- Supporting people with dementia to maintain their links with existing social groups and activities (church, pub darts team, line dancing, whatever they may be) for as long as possible
- Providing services at local level, even in villages where there may only be a few people with dementia
- Access to Admiral Nurses
- Contact names and numbers for help in emergencies
- Responsive support in the community to be provided by community psychiatric nurses
- Training for carers as soon as possible after diagnosis, covering the topics that carers have defined as being important, e.g. what is dementia, different kinds of dementia, how to deal with unexpected behaviour and new patterns of behaviour, legal issues such as dealing with estates, medication – what's available, the importance of keeping healthy, nutrition, lifting and handling, support available for carers, benefits and finance, and so on.
- Life story creation: familiar photos, souvenirs, letters etc, collected in a book, box or file, together with details of the likes and dislikes, choices and preferences of the person with dementia, to help that person remember, and to help new people to get to know them and work with them in ways that will suit them
- Training for all GPs

- Training for all hospital staff who could be involved in caring for someone with dementia
- Training for all day care staff who care for people with dementia
- Training for all care home staff who do, or may, care for people with dementia
- Training for all other staff who do, or may, care for people with dementia, such as those working in sheltered housing
- Providing support for people with dementia and their carers at times of transition
- Respecting and valuing people with dementia

There are examples of some aspects of best practice in many areas of the county, but overall it is very patchy.

Findings: Key Issues

Seek the views of local NHS commissioners and VCS organisations and groups on the key issues in Staffordshire in relation to dementia

The key issues raised were:

- Increasing prevalence of dementia

Statistics suggest that as people live longer dementia will become more prevalent with a greater percentage of the population suffering from it. (carer)

- Gap between statistical prevalence and diagnosed prevalence, which means that many people in need may have no access to existing services

We know there's a high rate of dementia and also concealed dementia, people who haven't yet presented to GPs or statutory agencies. (professional)

- Ageing population – more people will develop dementia, the average age of carers will rise

A third of people over the age of 85 have some form of memory impairment caused by dementia. The good side is that two-thirds don't, but as our ageing population grows, that third is going to increase incredibly. (professional)

- A strong desire from everyone for people with dementia and their carers to be able to manage in the community for as long as possible

There are some fairly simple things that can be done to support a person at home, it will require funding but the savings that can be identified are potentially huge. (professional)

- The stigma of dementia (see page 19 above for details)
- Lack of early diagnosis and early intervention which could save so many problems for people with dementia and their carers, as well as reducing expenditure and other demands for service providers

At the moment only one-third of patients are getting a formal diagnosis of dementia. What that actually means, out there in their own homes or nursing homes or acute hospitals is a whole raft of people without a formal diagnosis, this is when you get the crisis admissions into acute care because the family can't cope, they're not being supported. (professional)

- Insufficient service provision for people with dementia and their carers – nowhere near enough day care, affordable sitting services, residential respite, outreach support, training for carers, responsive services within

office hours, out of hours crisis support, dementia cafés, or services for younger people with dementia

The three of them want work, they're all in their late 50s, when he's stuck in the house 24/7 he gets really frustrated. He wants to go out and do a bit of work, stacking shelves, the girl told him straight, the only way he can do it is more funding and somebody to stop with him for the hours, I can't afford to do that every day. We go out everywhere, come 9.30 or 10 in the morning we're out, I've got the others in the car, otherwise all they do is sit and vegetate in the house. Another is desperate to get out in the community, he's 52 or 53, there's nothing for him. This lad is 59, they should be out working, as long as they're supervised. Hopefully when we get back he'll be in the garden this afternoon, just for something to do. (carer)

- Lack of support for carers

What worries me is if anything happens to me. She'd be with me but wouldn't know what to do if anything happened to me. (carer)

It's the breaks for carers, we need the carers, they're literally holding it together, it does feel like sticking a plaster over a gaping wound. (professional)

We've got to build in respite for carers, they're saving us an awful lot of money. (professional)

Carers don't get enough support. (person with dementia)

As a carer I'm 24/7 apart from when she's in the day centre. (carer)

The carer has to alter their pattern of life... I used to play a lot of bridge, but if you get a babysitter in, it's £14 an hour and bridge takes three hours. (carer)

- Staff who are inexperienced and untrained in working with people with dementia: particularly paid carers, care home staff, hospital staff and GPs

Carer agency staff are poorly trained if at all in dementia. There's a lack of dementia training for care home staff even in places with EMI beds, it's very variable. (professional)

- General lack of awareness of dementia, its effects and its progression

People just do not know enough about it, and they shut their eyes anyway, they don't want to know about it until something hits them. It was scary with my husband, I just thought he was getting old and doing silly things etc, then after a while you realize there's far more to it than that. (carer)

- Isolation of people with dementia and their carers – friends are lost, also difficulty maintaining relationships and social life if housebound

When I had my husband at home, there was nowhere like this [dementia café]. It's a lifeline for some of them. I couldn't even go to the toilet without him. People don't understand what it's like. (carer)

A lot of people round here have big families, with a member of the family always near if they want a day out. My experience is that I have three daughters who all went away to uni and never came home to live, two in East Anglia and one in Warwickshire, my sister is in Cumbria and that's the extent of my family. (carer)

The alternative [to day care] is to sit in my bungalow on my own. My family live at the far extremes of the country... I'd like to walk round places where I used to live and have a look at some of the old buildings, but it's impossible for me to do that, I get lost very easy so I don't chance it very often unless someone takes me by the hand. (person with dementia)

- Difficulties for people with dementia (and, in some cases, their carers) in managing direct payments

They're pushing direct payments, because it's easier for them, but what they haven't told you is that for people with dementia, direct payments aren't always suitable. I have to look after my wife, she can't look after her own payments. At the other end of the scale, in your 20s with Down's Syndrome, it gives you independence. If they pay you, you can't use council services, the day centre my wife uses, there's no-one in the private sector like it, and she couldn't go to the place she goes for respite care, the other ones we've looked at, I wouldn't let her go there. (carer)

You can go to someone who runs the direct payment for you, but it costs you more. (carer)

- Safeguarding for older people

He was still driving, he'd go to church and lose the car, they'd be looking all round the back streets for the car, eventually we had to persuade him not to drive because coming out of his home was quite dangerous. (carer)

- The national dementia strategy is very helpful, but locally there is too much strategy development and consultation, not enough service improvement

We've been lucky to have a national dementia strategy that has brought everything together so well. It has great aims, implementing it all may be beyond us in terms of funding at the moment, but the themes are something to work towards. (professional)

The need for a named "key worker" from Staffordshire social care and health has been acknowledged and promised at "Your Voice" conferences for the past three years, but as yet has not been implemented. (carer)

- Insufficient funding for adequate services

We are in an economic environment at the moment and I don't think people always are honest enough to say that, people know there are people losing jobs etc and it's not good out there, not doom and gloom but you have to be realistic with people, we don't have loads and loads of money, you can redesign things to be a bit better but you have to be honest about it. (professional)

- Too much service reconfiguration

There's been a restructure in the joint commissioning unit, there's potentially all sorts going on, the South Staffs PCT provider arm and social care and health are putting in a bid to develop a social care trust, although nothing can be done on that now until after the election, and there is the clustering arrangement for PCTs that I don't know a lot about at the moment but I know that's going on as well. All sorts of potential big organisational changes. (professional)

- Good quality services being replaced with poorer quality services

Our district council area has been split into five localities, we have evidence that we need two support workers, but it was expensive. The argument is that our dementia support worker will be replaced by six information workers from September to cover the whole PCT area, but they will be lower level workers than our dementia support worker and are to give signposting and information only. A condition like dementia needs emotional support, not just information. I'd have preferred to have another dementia support worker. The grades they are coming in at is much lower, they are covering a big geographical area and they're quite emotionally draining posts. (professional)

- Not enough of the continuity and familiarity that people with dementia need

Because of the nature of the illness people respond well to continuity. (professional)

With a TIA [mini-stroke], there's not much anyone can do about it, my wife comes round in the house, she's quite happy, she comes round on a trolley in A&E, it's disturbing, you have to weigh up the pros and cons. (carer)

Consistency of caring, you don't get the same person, even at the same time, I know people get sick. When I've asked for the same person in the morning for as long as they're working, they say 'we don't like familiarity with the patients'. People with Alzheimers go by face not usually by name, they recognise people. If they get a stranger, especially if it's a young one, it's 'who are you?', 'what's this young one dealing with me for?' We get stuck with it the rest of the day and it can upset the routine... The companies don't agree with it because they say you're getting too familiar. In my opinion it's what the patients want. (carer)

- Need for information and support at times of transition (see pages 16–18 above for more details)
- Geographical variations – services are not consistently available even within Staffordshire: there are differences between the two PCTs in how they address and fund dementia services, also provision is scarce in many rural areas
- Dementia is an illness so services for people with dementia should be provided free of charge by the NHS

Drug addicts or anyone like that, they get free care, this is a disease, you know what I mean? It's wrong when you've got to pay. I've written to Gordon Brown, I've had a reply but it's a waste of time. I had a reply off the health secretary as well. What's the use of saving, today? If I was there now, I wouldn't save. (carer)

What you can't get over is, there's a law, and the law says that if you're suffering from an illness, the NHS will look after you for free, which is what we've paid into all our lives. Now it's up to PCTs to decide whether you need nursing care. People with dementia suffer from an illness, they don't necessarily need nursing care but things everyone else takes for granted they can't do because of an illness so it should be NHS. (carer)

Funding issues, I believe should be looked at in regard for services being free, care being paid for as nearing end of life. People are having to pay for care, home care. I feel it should all be free. The health service is from cradle to grave. (professional)

- Different people with dementia have different needs but the funding level is the same which is not fair or sensible

The people I look after, some need three people to assist at times, and some need one person for most of the day, that is not reflected in the funding, it's not different for people who just sit in the chair all day, there's no differential in funding. (professional)

- Inadequate support for people with dementia in hospitals

He'd be so scared in hospital, I had to go in and feed him. They put pads on him in hospital but he wasn't incontinent. I said PLEASE don't. There was one staff nurse who insisted, she said she hadn't got time to take him to the toilet. The ward sister was lovely, but the staff nurse, I wanted to go and sit with him, she said, 'Why are you bothering? There are places for people like that.' (carer)

One thing I do find really strange is, when my mum goes into hospital, they'll walk in and ask, 'Are you allergic to anything?' and she says, 'No,' and they just stick a needle in her. She's got dementia, she wouldn't know. In hospital, apparently, they're not allowed to put 'dementia' over the bed because it's

labelling people. They'll put 'diabetic' but not 'dementia'. The nurses come and ask her things, and she's going, 'yes, no,' she doesn't know, why do they ask her and not me? It just seems like lack of communication all round.

(carer)

My wife just went in with a broken knee and had a plaster on for eight weeks. At meal times when you explain what the position is it doesn't make a difference. PALS try to help, but my wife lost, in eight weeks, ten pounds in weight. They said, 'How do you know?' I weigh myself and her every fortnight, as mother nature planned us. She lost so much weight, when she was discharged she went on extended nursing care, in Bradwell, the service there is first class. They're treated as individuals, they check them every hour through the night, the food is excellent, they feed them if they can't feed themselves and there's always cups of tea and biscuits. She wouldn't still be here now if she'd been in hospital longer. (carer)

Nurses don't understand because they're not trained for dementia. Time and time again, with medication, they say if she refuses it they can't force her. I was giving it to her at night time, if they don't take it they can't do anything. Carers can struggle to get them to take pills, you put them in their mouth and they don't know what to do with them. They spit them out sometimes. They should know when they go in to hospital what tablets they're on and what they are for, they know all that. They've got a wizard system at Bradwell, they put the tablet in a thing with a bit of water, and tell them to take it. Need to not ask them, just tell them. (carer)

[Talking of a man who'd had a 'big bleed from below the waist' when his niece and main carer was abroad supporting other family members through a health crisis, and was also trying to manage the care of her uncle by telephone from overseas] They kept insisting this was a nosebleed, I even spoke to the crisis man because nobody would take him into hospital, they were arguing over whether it was social. Eventually his daughter came, she'd lived in South Africa, his first wife had died when she was three, she'd had no relationship with him, she'd gone to a grandma, but she was coming to see him, she was advised to abandon him in casualty because it was the only way to get him in. (carer)

Findings: Known Areas of Concern

Engage with the wider community where appropriate to understand specific issues or test known areas of concern in relation to dementia services in Staffordshire

At a consultation day held by Staffordshire LINK on 26th January 2010, the following issues were raised:

- Dementia strategy document
- What's the national dementia strategy doing for people in Staffordshire
- Assessment: GP support
- Dementia care in care homes
- Training for families – strategies for coping
- Information for families

These issues were discussed with professionals, carers and people with dementia. In general, the national dementia strategy met with approval, although there is great uncertainty about how the work will be funded. It is clear from this research that there is a big overlap between the 17 objectives set out in the national strategy (see appendix 6 for details) and the aspirations of people with dementia, their carers, and many professionals in the county. In terms of what the strategy is doing for people in Staffordshire, in March 2010, the county's Health Scrutiny Committee and Social Care Scrutiny Committee identified tangible progress against each of the first 14 objectives from the national strategy. Full details are in appendix 7.

With reference to the issues raised at the consultation day, this research has shown that assessment is generally seen as inadequate, both for people with dementia and for their carers, although there are a few exceptions. Dementia care in care homes can be very good but is often inadequate.

Training for carers is good where it exists, and more is planned in the South Staffs PCT area, with funding for a sitting service if necessary. There is less training for whole families, and one participant in the research suggested that the needs of young carers of family members with dementia are not being addressed. Some carers have difficulty accessing existing training because of work and other commitments. Information is often hard to come by, and first points of contact such as GPs and hospitals often don't have, or don't pass on, the information that families need.

A number of other specific issues were raised during the research process, and these are covered in other sections of this report.

Findings: Service Reconfiguration and Development

Identify any plans for investment, efficiency, service development or reconfiguration

This is not a complete picture of the situation in Staffordshire – that would be a complex piece of research in itself – but the researchers did identify a number of plans for investment, efficiency, service development and reconfiguration. Service reconfiguration, in particular, seems to be a continual process in the county, which is not always to the advantage of service users. Specific plans and actions identified by the researchers are set out below.

South Staffordshire PCT is investing £695,000 in dementia services in 2010–11. A sizeable consultation exercise took place in mid-2009 to identify priorities for this money, which will be spent on memory clinics in primary care, six dementia information workers, training for GPs and health professionals, and training for carers and people with dementia (including respite if carers need it to allow them to attend). When that money has been spent, it will be necessary to find efficiency savings to enable further investment in communities and give families the support they need.

There is no equivalent investment by North Staffordshire PCT, who seem to be relying quite heavily on the third sector.

The third sector is investing as much as it can in services for people with dementia and their carers, in both the north and south of the county. Age Concern is developing four resource centres in the south, with a broad spectrum of day opportunity services. Over the last three years, the Carer's Association of South Staffordshire has run a dementia support worker project in the South Staffordshire district, but this has just come to an end. The Alzheimer's Society runs six monthly dementia cafes in the south of the county, in Tamworth, Stafford, Codsall, Burntwood, Cannock and Burton. Approach runs four in the north: in Biddulph, Cheadle, Leek and Newcastle. Approach also run a dementia navigator service, with paid workers supported by volunteers who work with families in the community to provide early intervention and support. Some of these services are wholly or partly funded from the statutory sector.

Some sheltered housing providers are developing dementia support.

In the south of the county, the PCT and social care and health are working towards integrated service provision. This will create efficiencies through closer working links, and prevent arguments about which of them should pay for someone's care.

The joint commissioning unit had a big restructure at the start of the current financial year, with existing staff taking on wider roles.

There are strong rumours of unification between district/borough councils, both within Staffordshire (e.g. South Staffordshire and Cannock) and across its borders (e.g. Staffordshire Moorlands and High Peak).

Service providers sometimes assert that continued provision of services can lead to dependency.

There are other support workers out there, the service is there, we're not taking that away from them, but it depends how you operate, whether there's a one-to-one available, if there's time that's great but it could encourage dependency. (professional)

This seems to ignore the fact that people with dementia, and those doing the often very difficult, demanding, and non-stop unpaid job of caring for them in the community, need services on which they can depend. Removal of such services, or insecurity of their funding, can cause extra stress for carers – which is the very last thing they need.

The evaluation [of the CASS dementia support worker post] said it was well needed and well delivered. There have been lots of tears from carers, professionals are also saying why are we stopping? (professional)

[service user speaking to everyone at a dementia café] We know the funding for this café has only been extended for a year, not three years as previously. It was announced at the previous café. It would be devastating if the café had to close. Also it must be hard for the workers. What can we do about it? Can we sell our café to people, let people know how important the cafes are to us, and to the people who organize it? I don't want it to change. Already I've actually spoken to two social services workers in the month that's expired. They readily took on board what I was saying, I really blew the organisers' trumpet which these people can't readily do, and said how much it means to us, it's a really important part of my life. They took notes and thanked me for making the statement that I made. We all see people all the time, whatever you're seeing them for, please think about blowing the trumpet, the message then comes through from us right round the circuit. (carer)

There is talk of a helpline for carers through Staffordshire Cares, but nothing definite about how this might be funded and managed, or about its proposed hours of availability.

Findings: How to Consult and Involve People

Propose where the LINK might best focus its attention in seeking the involvement of local people in influencing services developments and/or highlighting areas for improvement

Advice was sought from people with dementia, their carers, and professionals about how best to involve local people in influencing service development and highlighting areas for improvement. Suggestions were:

- Ask straightforward questions
- Go to where people already are: senior citizen groups, Women's Institute, Round Table, Lions, Masons, Townswomen's Guild, dementia cafés, GP surgeries, memory clinics, carers' groups, GP/PBC patient representative groups, adult care panel, day care centres, sheltered housing, community groups – don't expect people to come to you
- Small groups are better than big ones, as in big groups fewer people will speak because some people will be afraid to make a fool of themselves
- Use simple questionnaires for carers who don't go to groups, or visit them in their homes
- Advertise consultation events in the local papers
- Don't expect carers to want to take part in consultation; for many, time away from their caring role is very limited or non-existent, and they may be so overwhelmed that they don't have much time or energy to give to consultation
- If carers do want to take part, it may be necessary to provide a sitting service to enable them to do so
- For consultation events, it may be necessary to provide transport
- Bear in mind that carers may not always want to express their own needs in front of the person they care for
- Speak to staff of front-line services as they often have ideas to share
- Aim to speak to a good cross-section of people
- Don't promise anything you can't deliver
- Don't turn up wearing a uniform or badges – come in informal dress
- Don't let carers speak for people with dementia because you may not get accurate results, take the trouble to find out those people's own views, using appropriate techniques where necessary such as pictorial or symbolic questionnaires or Talking Mats
- When you want to involve people with dementia, it's best to ask them for their views about where they are or what they are doing at the time: if you want to know what they think of their lunch, ask them at lunchtime; if you want to know what they think of their transport, ask them when they're on the transport
- Make sure there's something in it for the people you're involving
- Don't make it too arduous

Appendix 1 – Questions for Groups

PREAMBLE: review purpose of research; independent researchers; anonymisation of interviewees' data; potential limits to confidentiality; permission to list organisation in the back of the report; any questions?

1. Please can you give us brief background details about your group and its history?
2. How many members do you have?
3. How do people find out about the group?
4. How often do you meet?
5. What do you see as the group's purpose?
6. What do you do in your meetings?
7. Are there any other dementia groups or services in the area that you use?
8. Do you collect any information about people's needs or experiences?
9. If yes, what do you collect?
10. Is it possible for you to share that information with us?
11. Do you collect any information about barriers in accessing services or gaps in services?
12. If yes, what do you collect?
13. Is it possible for you to share that information with us?
14. What do you think are the key issues/problems in Staffordshire in relation to dementia services for patients and carers?
(PROBE if not mentioned - At a consultation day on 26th January, the following issues were raised:
 - Dementia strategy document
 - Assessment – GP support
 - Dementia care in care homes
 - Training for families – strategies for coping
 - What's the national dementia strategy doing for people in Staffordshire
 - Info for families)
15. Do you have any involvement with LINK?
16. If yes, what is that involvement? If no, do you know why that is?
17. What is the best way for you to be involved?
18. How and where do you think LINK should best focus to seek involvement of local people including patients and carers, in:
 - a) Influencing service development
 - b) Highlighting areas for improvement
19. Is there anything else from your perspective that you think it might be useful for us to know about dementia services?

Appendix 2 – Participants in Research Interviews

1. Caroline Lingard, Senior Service Manager, Age Concern
2. Fiona Cozens, Senior Policy and Performance Officer, South Staffordshire District Council
3. Harry Ferguson, Staffordshire LINK member and carer (face-to-face interview)
4. Helena Payne, Dementia Support Worker, Carers' Association South Staffordshire
5. Julie Oxtoby, GP and Clinical Executive member for North Staffs PCT
6. Laura McCormick, Manager, Park Farm Lodge (independent nursing home)
7. Liz McCourt, Practice-Based Commissioner, South Staffs PCT (East)
8. Mac Cock, Assistant Chief Officer, Carers' Association South Staffordshire
9. Marie DuQuesnay, District Director, Social Care and Health
10. Sally Young, Commissioning Manager for Dementia and Older People's Mental Health, Staffordshire Joint Commissioning Unit
11. Tina Randall, Health Overview and Scrutiny, Staffordshire County Council (telephone conversation rather than full interview)
12. Will Boyce, Chief Executive, Approach (face-to-face interview)

(NB: the researchers tried hard to secure an interview with someone from a local authority care or nursing home, but in the event were unable to do so.)

Appendix 3 – Interview Questions

PREAMBLE: review purpose of research; independent researchers; anonymisation of interviewees' data; potential limits to confidentiality; permission to list name and organisation in the back of the report; any questions?

1. Please can you give me a brief background sketch of your service and your role within it?
2. Do you have any information that identifies local health needs in relation to dementia that you could share with us?
3. Do you have any information regarding variations in need across different geographic areas or sectors of the population and different stages of the disease that you could share with us?
4. Do you have any information that identifies patient/public experience or concerns in relation to dementia services in Staffordshire that you could share with us?
5. Do you have any information regarding barriers in access to services or gaps in service, that you could share with us?
6. Do you have any information that identifies performance or progress in Staffordshire against national standards that you could share with us?
7. Do you have any examples of best practice that you could share with us?
8. Do you know of any local development groups in the districts that focus on dementia?
9. What do you think are the key issues in Staffordshire in relation to dementia services for patients and carers?

(PROBE if not mentioned - At a consultation day on 26th January, the following issues were raised:

- Dementia strategy document
- Assessment – GP support
- Dementia care in care homes
- Training for families – strategies for coping
- What's the national dementia strategy doing for people in Staffordshire
- Info for families)

10. Does your organisation have any plans for investment, efficiency, service development or reconfiguration?
11. Do you know of any other organisation's plans for investment, efficiency, service development or reconfiguration?
12. How and where do you think LINK should best focus to seek involvement of local people in:
 - a) Influencing service development
 - b) Highlighting areas for improvement
13. Is there anything else from your perspective that you think it might be useful for us to know about dementia services?

Appendix 4 – Documents Analysed

National Sources

1. Department of Health. February 2009: Living well with dementia, a national dementia strategy.
2. Department of Health. February 2009: Accessible summary. Living well with dementia, a national dementia strategy.
3. Department of Health. July 2009: Living well with dementia, a national dementia strategy. Implementation plan.
4. Department of Health. June 2009: Living well with dementia, the national dementia strategy. Joint commissioning framework for dementia.
5. Alzheimer's Research Trust: Dementia 2010, The economic burden of dementia and associated research funding in the UK.
6. National Collaborating Centre for Mental Health 2007: The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care.
7. NHS & SCIE. November 2006: Supporting people with dementia and their carers in health and social care.
8. NHS & SCIE. November 2006: Information for people who use NHS and social care services. Supporting people with dementia and their carers in health and social care.
9. NHS & SCIE. November 2006: Quick Reference Guide. Supporting people with dementia and their carers in health and social care.
10. Department of Health. February 2009: Consultation response and analysis. National dementia strategy.
11. The National Care Forum. April 2007: Key Principles of person-centred dementia care. Statement of best practice.

Internet Sources

This is a list of the guidance and best practice examples listed in the Joint Commissioning Framework for Dementia.

Objective 1

<http://www.scie.org.uk/publications/guides/guide03/framework/index.asp>
<http://www.scie.org.uk/publications/elearning/mentalhealth/index.asp>
<http://www.scie.org.uk/publications/elearning/mentalhealth/mh05/index.asp>
<http://www.nice.org.uk/Guidance/PH6>
<http://www.scie.org.uk/publications/briefings/briefing26/index.asp>
<http://www.scie-socialcareonline.org.uk/default.asp>

Objective 2

<http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentsservice/memoryassessmenthome.jsp>
<http://www.scie.org.uk/publications/misc/dementia/dementiafullguideline.pdf>
<http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11600>

Objective 3

<http://www.scie.org.uk/publications/misc/accessguidelinespublications.pdf>

<http://www.scie.org.uk/publications/misc/dementia/dementia-understanding.pdf>

<http://www.scie.org.uk/publications/briefings/briefing03/index.asp>

<http://www.scie.org.uk/publications/guides/guide15/index.asp>

<http://www.scie.org.uk/publications/reports/report15.pdf>

<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>

<http://www.scie.org.uk/publications/elearning/mentalhealth/mh06/index.asp>

Objective 4

<http://www.scie.org.uk/publications/misc/dementia/dementia-understanding.Pdf>

<http://www.scie.org.uk/publications/guides/guide15/index.asp>

<http://www.scie.org.uk/publications/guides/guide03/needs/info.asp>

<http://www.scie.org.uk/publications/guides/guide03/minority/index.asp>

<http://www.scie.org.uk/publications/guides/guide03/abuse/index.asp>

<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>

<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

Objective 5

<http://www.scie.org.uk/publications/positionpapers/pp10.asp>

<http://www.scie.org.uk/publications/guides/guide17/files/guide17.pdf>

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

<http://www.scie.org.uk/publications/guides/guide15/index.asp>

Objective 6

<http://www.scie.org.uk/publications/guides/guide10/files/guide10.pdf>

<http://www.scie.org.uk/publications/briefings/files/briefing20.pdf>

<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>

<http://www.scie.org.uk/publications/reports/report20.asp>

<http://www.scie.org.uk/publications/positionpapers/pp10.asp>

Objective 7

<http://www.scie.org.uk/publications/guides/guide03/index.asp>

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

<http://www.scie.org.uk/publications/reports/report15.pdf>

Objective 8

<http://www.scie.org.uk/publications/misc/hospitaldischarge/index.asp>

Objective 9

<http://www.scie.org.uk/publications/briefings/briefing12/index.asp>

<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

Objective 10

<http://www.scie.org.uk/publications/briefings/briefing28/index.asp>
<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>
<http://www.scie.org.uk/publications/reports/report15.pdf>
<http://www.scie.org.uk/publications/guides/guide15/index.asp>

Objective 11

<http://www.scie.org.uk/publications/guides/guide15/index.asp>
<http://www.scie.org.uk/publications/briefings/briefing01/index.asp>

Objective 12

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

Objective 13

<http://www.scie.org.uk/publications/reports/report15.pdf>
<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>
<http://www.scie.org.uk/publications/guides/guide03/process/understanding.asp>
<http://www.scie.org.uk/publications/guides/guide03/framework/index.asp>
<http://www.scie.org.uk/publications/misc/dementia/dementia-grg.pdf>
<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>
<http://www.scie.org.uk/publications/misc/mca.asp>
<http://www.scie-peoplemanagement.org.uk/>
<http://www.scie.org.uk/publications/guides/guide03/needs/main.asp>

Objective 14

<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

Objective 15

No evidence available

Objective 16

<http://www.scie.org.uk/publications/guides/guide03/needs/index.asp#dem>
<http://www.scie.org.uk/publications/guides/guide15/index.asp>
<http://www.scie.org.uk/publications/briefings/briefing03/index.asp>
<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>
<http://www.researchregister.org.uk/default.asp>
<http://www.scie-socialcareonline.org.uk/default.asp>

Objective 17

<http://www.nice.org.uk/Guidance/CG42#implementation>
<http://www.scie.org.uk/publications/knowledgereviews/kr16.pdf>
http://www.nice.org.uk/using-guidance/implementationtools/howtoguide/145how_to_guide.jsp

Staffordshire Sources

1. Health Scrutiny Committee and Social Care Scrutiny Committee – 5 March 2010. Improving Services for People with Dementia.
2. Health Scrutiny Panel, 20th October 2009, A review of voluntary carers in South Staffordshire.
3. Information for service planning. March 2010. Bev French, County Commissioner, Older People.
4. Staffordshire Joint Strategic Needs Assessment. Estimating current and future prevalence of mental health and learning disabilities in Staffordshire (DRAFT). August 2009.
5. Dementia Services in Staffordshire Timeline (via Sally Young).
6. Staffordshire Joint Commissioning Unit. South Staffordshire Dementia Service Improvement Board Dementia Strategy August 2008.
7. Celebrating good practice in dementia care.
8. The National Dementia Strategy – Listening and Engagement. A Report on the Informal Consultation Process in the West Midlands Region. March 6, 2008.
9. JCU. 5 Steps to Accessible & Inclusive Projects – Dementia service developments in South Staffordshire. Equality Impact Assessment.
10. Consultation Document. 2007. Proposal to Develop a Specialist Centre for People with Organic Mental Health Needs (Dementia) for North Staffordshire and Stoke on Trent.
11. Evaluation of consultation report on proposal to develop a specialist centre for people with organic mental health needs (dementia) for North Staffordshire and Stoke-on-Trent. November 2007.
12. Health Scrutiny Sub-committee. 8 October 2008.
13. Newcastle Under Lyme Borough Council, letter to North Staffordshire Primary Care Trust. October 2007.
14. A Joint Commissioning Strategy for Services for Older People in Staffordshire 2008 – 2012. Staffordshire Joint Commissioning Unit. October 2008.
15. Health Scrutiny Committee – 5 January 2010.
16. Staffordshire County Council/South Staffordshire PCT. Older people's mental health: Assessment of Needs and Services. March 2008.
17. A dementia support worker service evaluation. Centre for ageing and mental health/ Staffordshire university.
18. Case studies. Supporting people with dementia in Staffordshire. Staffordshire County Council/ North Staffs NHS/South Staffs PCT.
19. Transcript. Chamber Debate on Staffordshire Cares. 26 October 2009.
20. Staffordshire LINK consultation event at Yarnfield Park. 26th January 2010.
21. Staffordshire Moorlands District Council. Health Scrutiny Panel minutes. 3rd November 2009.

Appendix 5 – Total Population Projections for Over 65s in Staffordshire and Districts³

County estimated total population

	2010	2015	2020	2025	2030
People 65–69	47,800	56,200	50,000	52,800	60,100
People 70–74	38,000	44,600	52,700	47,300	50,200
People 75–79	29,000	33,800	40,100	47,800	43,100
People 80–84	21,200	23,700	28,500	34,200	41,000
People 85+	18,500	22,400	27,300	34,800	44,200
All people 65+	154,500	180,700	198,600	216,900	238,600

County % change from 2010

	2015	2020	2025	2030
People 65–69	18%	5%	10%	26%
People 70–74	17%	39%	24%	32%
People 75–79	17%	38%	65%	49%
People 80–84	12%	34%	61%	93%
People 85+	21%	48%	88%	139%
All people 65+	17%	29%	40%	54%

District/borough estimated total population of over 65s

	2010	2015	2020	2030
Cannock Chase	15,700	18,400	20,400	25,200
East Staffordshire	19,000	21,900	24,300	31,000
Lichfield	19,700	23,300	25,600	30,300
Newcastle-under-Lyme	22,800	25,700	27,600	32,200
South Staffordshire	22,200	25,600	28,200	33,700
Stafford	24,900	29,000	32,000	38,000
Staffordshire Moorlands	19,900	23,200	25,400	30,400
Tamworth	10,600	13,300	15,300	18,500

³ Tables taken from *Information For Service Planning*, JCU 2010

District/borough % change from 2010

		2015	2020	2030
Cannock Chase		17%	30%	61%
East Staffordshire		15%	28%	63%
Lichfield		18%	30%	54%
Newcastle-under-Lyme		13%	21%	41%
South Staffordshire		15%	27%	52%
Stafford		16%	29%	53%
Staffordshire Moorlands		17%	28%	53%
Tamworth		25%	44%	75%

Appendix 6 – Objectives from the National Dementia Strategy

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 and set out in Annex 1.

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.

Appendix 7 – Local progress against Objectives 1–14 from the National Dementia Strategy (March 2010)

Objective 1

- Training for GPs and carers in South Staffordshire Primary Care Trust (SSPCT) with new Local Development Plan funding. Staffordshire Social Care Workforce Partnership (SSCWP) training programme for dementia awareness across the Private, Independent and Voluntary (PIV) sector. South Staffs District Dementia Project funding additional training for care/nursing home staff.
- Funding for Care Home intervention services in North Staffordshire Primary Care Trust (NSPCT) and SSPCT through healthcare providers.
- Biennial conference in North Staffs to showcase good practice across organisations.
- Dementia, Diagnosis & Beyond Conference hosted by Stafford University and
- Shropshire and Staffordshire NHS Foundation Trust (SSHFT) for South Staffordshire.

Objective 2

- SSPCT – Additional LDP Investment in memory clinics across the PCT, also dementia awareness training for GPs and carers.
- NHS North Staffs (NHSNS) – Review of existing memory services models against national good practice.
- Development of pathway routes to social care.
- Use of Just Checking Assistive technology across County as part of assessment process highlight abilities as well as dependencies, provides carer reassurance and supports independent living.

Objective 3

- Dementia Advisor post. SSPCT creating posts in each Practice Based Commissioning area. Carers Grant funding to support this and extend to NHSNS in Summer 2010. This process will replace South Staffs District Council Dementia Project which ends in March 2010 and Alzheimer's Society two dementia advisors – funding ceases in September 2010.
- Supporting People funding for Approach Dementia Advisor plus support workers in NHSNS and Accord Dementia support posts in SSPCT.
- Funding for Alzheimer's and Approach Cafes which also provide information and support to people with dementia and carers.

Objective 4

- SSPCT – Pathways being developed for appropriate referral to Social Care, and a menu' of third sector services available and those services which are free at point of delivery/assessed for contributions.
- SSPCT – Investment in memory clinics, dementia advisors and training for GPs and Carers across the PCT.

- Alzheimer Cafes, Approach Cafes and MASE group. (Monthly support evenings.)
- Review of day care for dementia as part of Social Care and Health review of all day provision.

Objective 5

- Multi-agency Older Peoples Mental Health strategy group across North Staffs & biennial conferences across North Staffs/Stoke.
- Dementia, Diagnosis & Beyond Conference hosted by Stafford University and SSHFT for South Staffordshire. 27/01/10.
- South Staffs District Council Dementia Local Strategic Partnership group.
- District Dementia Leads group.
- Dementia Network for SSPCT area is multi-agency.

Objective 6

- New Domiciliary Care contract links to dementia advisors & personalisation. Training available for Dom Care workers and Care/Nursing Home Staff. Training also available for carers at home.
- Review of day care services for dementia. Half day planned in February with
- stakeholders to focus on improving current services.
- Stay at Home scheme in East Staffs District – Community Psychiatric Nurse support to person with dementia at home phased to prevent hospital admission.

Objective 7

- Carers Grant funding to extend to top up funding for dementia care advisors across Staffordshire at district level. Respite Care available at home, in day services & care home settings.

Objective 8

- Joint Commissioning Unit (JCU) involvement with the Frail Elderly Project at Burton Hospital Foundation Trust picking up dementia workload. Joint appointment of Frail Elderly Consultant for SSPCT & Hospital to work in and outside hospital.
- Mid Staffordshire Foundation Trust now attending Dementia Service Improvement Board (SIB).
- Frail elderly project at University Hospital of North Staffordshire NHS Trust (UHNS) includes dementia. UHNS providing staff training from combined healthcare.

Objective 9

- Working with intermediate care to deliver high quality services and to include people with dementia in intermediate care services. Pooled budget funding for a specialist 'step down' assessment and care planning service in a local authority care home in North Staffs. Pooled budget funding for a 'staying home' scheme which provides intensive support and assessment at home as step down or step up. Shared learning from care home investigations.

- Intermediate care work stream of frail elderly project at Burton Hospital.

Objective 10

- Extra care housing developments for people with dementia across the county. Project working on building in best practice of integration of NHS with extra care services.
- Working with existing housing provision to build dementia awareness and develop appropriate support to help people remain within their community. Supporting People funded services linked to home improvement agencies.
- Assistive technology (AT) & telecare project manager is trialling and distributing wide range of AT to carers. Increasing use of standalone technologies such as memominder. Largest participant in regional automatic pills dispenser project and active engagement of community pharmacists in supporting people with dementia and their carers in improving medication management. Close working with MedlinkWMM and Staffordshire University to develop new technologies.

Objective 11

- Care Home Intervention Services available in both PCT areas to provide advice and training to care homes for people with dementia.
- SSPCT Care home Service improvement Programme for End of Life (EOL) Care for people with dementia.
- Training available through SSCWP.
- 'Lessons Learnt from care home investigation' half day being pulled together by JCU in New Year.
- SS District Dementia project funding purchase of games to work with people with dementia and care home staff.
- Review with PCTs of use of anti-psychotic drugs and alternatives.

Objective 12

- Working with EOL teams for NHSNS & SSPCT, as well as EOL Lead for SSHFT to include people with dementia in EOL pathway. New Dom Care contract includes links to EOL pathways.

Objective 13

- Links to SHA workforce leads. Supporting regional project to develop dementia advisor role. Creating dementia advisors for SSPCT using new Integrated support worker model.

Objective 14

- Joint Strategic Needs Assessment work on future predicted growth of dementia across the county.
- Creation of Dementia Strategies in North & South.
- Completing the West Midlands Needs and Gap analysis with partner involvement.
- Dementia SIB in the South.
- Older People's Mental Health Strategy Group in the North.
- Commissioning additional memory services, training and dementia advisors in SSPCT area.

- Working together on correct protocols for drugs according to National Institute for Health and Clinical Excellence guidelines.