

Appendix B

Qualitative needs analysis

1. Engaging with people

Ways we engaged with people to inform the consultation paper

Exploratory work with key individuals and groups (May- July 2008)

- 1:1 interviews with stakeholders, conducted by members of project team
- Focus groups with service providers
- Attending voluntary sector activities

Qualitative needs analysis

Methodology for engaging with stakeholders

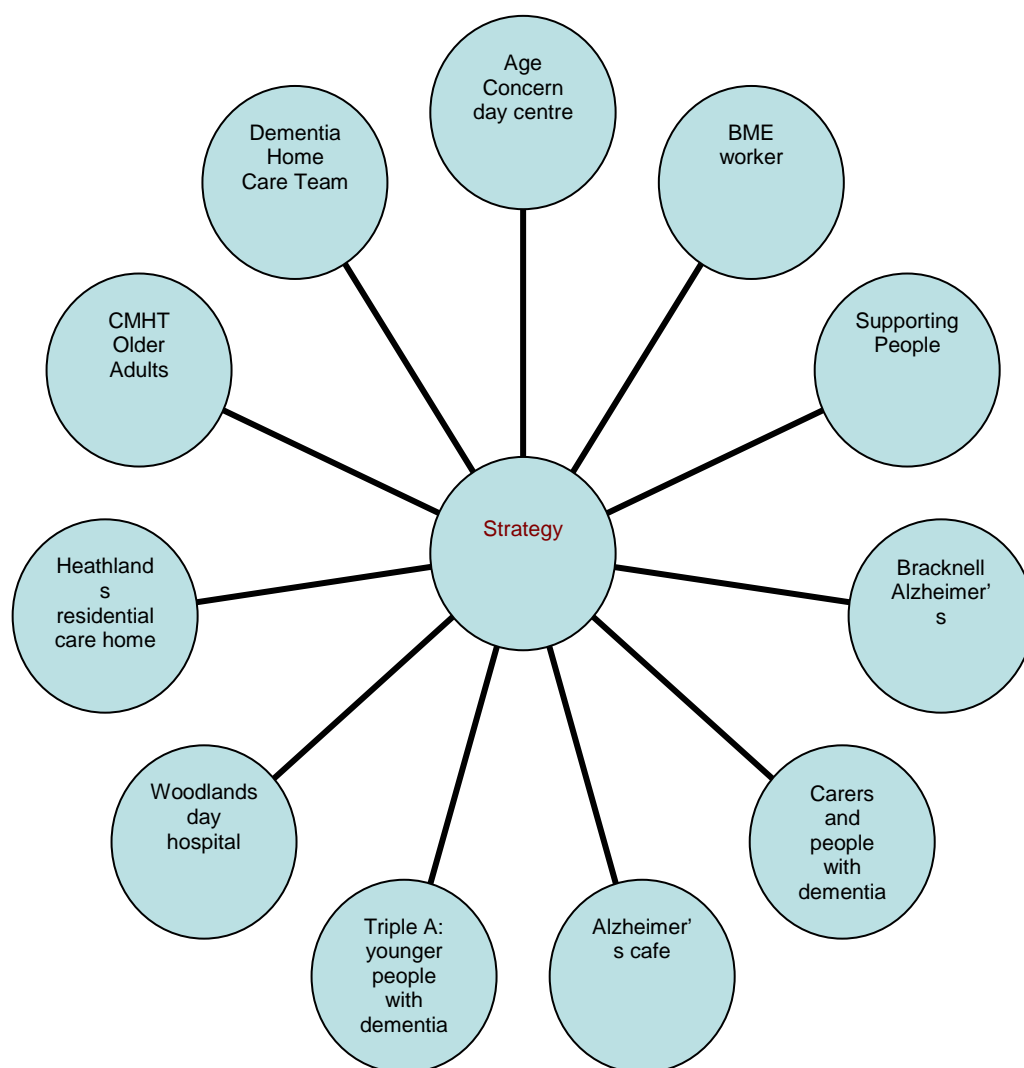
- Project team identified existing groups of people who use dementia services, carers and other stakeholders, and agreed appropriate ways to approach and engage with these people
- Project team agreed and identified those who may be seldom heard, and agreed appropriate ways to enable the experiences of minority groups to inform the needs analysis
- Existing qualitative data was identified
- Research tools (different interview guides appropriate for different groups and focus group guides) were developed with the project team
- Ways to feedback findings and opportunities for further comment were agreed.

In the exploratory work to develop the dementia commissioning strategy, it was essential that the key stakeholders in dementia care and support were involved. Views of people and groups who may be seldom heard in the Council's planning processes were actively sought, such as views regarding dementia support for Black and Minority Ethnic communities and for people with a learning disability. We also engaged with people who have dementia, carers, people who work in social care, health, the voluntary sector and other stakeholders, to obtain a wide range of views and perspectives on the future direction of support.

In the development of the interview guides and focus group guides we wanted to explore different aspects of current dementia care and support, as well as people's aspirations for future support. Interview guides were tailored to be appropriate to the individuals we were engaging with. For example, the interview guide for people with dementia was short and asked simple questions, whereas the interviews conducted with key professionals, the voluntary sector and carers were more detailed so we could gain as much information as possible. Guidance was also produced advising how to gain consent and interview people with dementia.

Existing dementia support groups in the voluntary sector were approached and discussions about the future of dementia support and services in Bracknell Forest were facilitated.

The figure below illustrates the range of groups and individuals we engaged in the qualitative needs analysis.



Findings

Overview

The data collection was carried out from May- July 2008. In total we conducted:

- 6 interviews with carers and former carers
- 10 interviews with people with dementia, including younger people with dementia
- 13 interviews with people involved in dementia support, from the statutory and voluntary sectors
- 3 focus groups with providers of dementia support (17 people)

We also attended 2 events organised by the voluntary sector organisation Triple A, which were attended by people with dementia, carers, former carers and people involved in dementia support in a professional capacity. A thematic analysis was employed to analyse the interview and focus group data.

Throughout the analysis of the survey data, there were several cross-cutting themes that emerged around the vision for dementia support and the context in which support should operate: **social inclusion and the importance of social contact**, a **holistic** approach, **access**, **community based** support and **flexible support to meet individual need**.

As the questions asked were slightly different for each group of people, the data from each group was analysed separately. Each question was analysed and themes and issues that related to more than one area were identified.

Views from people working in dementia support

We asked people from statutory and voluntary agencies who worked in dementia care and support several questions about what worked well, what did not work so well, where there were gaps and how we could improve access to dementia services.

1. What support and services work well?

In response to this question, two broad themes arose: good practice and models of care, and the value of voluntary sector support. Dementia support is highly regarded locally. One interviewee, who works across local authority areas, commented

‘The dementia services in Bracknell Forest are an excellent set-up’.

Multi-disciplinary teams

The people who participated in interviews and focus groups were in agreement of the benefits of having a responsive multi-disciplinary team to provide support to people with dementia. The Bracknell Forest Community Mental Health Team for Older Adults (CMHT OA) provides this service locally.

“Having the CMHT OA under one roof is very good. As there is a whole group of professions there, support is more accessible to people. It gives a better service for service users and carers”.

“The multi-disciplinary team at the CMHT OA works well. (The voluntary sector) have good relationships and there is a prompt response when you contact them regarding a person who is having a problem”.

Value of current services

People felt there were a variety of services available to meet the needs of people with dementia. It also emerged that these services are supported by assistive technology and the introduction of people receiving medication earlier.

“The Dementia Home Care Team is excellent”.

“The Dementia Home Care Team is an excellent service but it is a shame that this cannot be offered to all people with dementia and their carers”.

“The sleep-over service at Heathlands is very good. You have to pay for it, but carers can get money back through the carers grant”.

“People like the day hospital”.

“At Heathlands residential home it is like a big family where staff and residents all know each other and it is a good atmosphere. People know they can come to staff and there is more bonding”.

Models of care

When exploring why these services were good, several themes arose about what it is that makes particular services so valuable: dedicated staff, positive relationships, information, facilitating ‘normal’ activities for people with dementia, longer hours of day support and continuity of care. Any care and support provided should also be mindful of safeguarding issues, as people with dementia can have risk factors for safeguarding issues such as social exclusion and reliance on others.

“(The team) are really genuinely interested in the people”.

“The Dementia Home Care Team have a lot of contact with families. They keep communication going and the family involved. This helps to maintain and enhance family relationships. Carers take time to get to know new service users. They observe the home situation, build up trust and relationships, a get a gradual ‘foot in the door”.

“People attending the memory clinic are automatically given information about the local support available”.

“A ‘Supporting People’ support worker can signpost and arrange adequate support for people”.

“The Dementia Home Care Team take people out shopping and out for lunch at least once a month”.

“The longer days at Heathlands day centre and flexibility with days and hours works well”.

“Continuity of care from Dementia Home Care Team. The team is organised into 2 small teams of 3 people which can cover an amount of people using services. The people using the service get used to the 3 carers and there should always be someone familiar to the person to provide their care if someone is off sick or on holiday”.

“Safeguarding issues should be a key theme of any commissioning strategy”.

Voluntary sector support

Everyone we spoke to highlighted the excellent support offered by local voluntary organisations such as Triple A, Bracknell Alzheimer’s and the Age Concern day centre. Aspects that make these services good emerged from the data. These aspects included flexible use of funding, maintaining the independence and quality of life of people with dementia, a holistic approach and good links with statutory services.

“The voluntary sector provides an invaluable service to people with dementia and their carers”.

“Triple A supports younger people with dementia. This maintains skills by doing lots of ‘normal’ activities”.

“Age Concern do a pampering ladies day, and I think this is a good idea”.

“CMHT OA support the Alzheimer’s café once a month on a Friday evening. Staff take it in turns to attend and support the evening”.

2. What support and services do not work so well?

On analysis, the responses to this question resulted in several emergent themes.

Home care

The people we spoke to identified several challenges with home care. These included carers not having the appropriate skills to work successfully with people with dementia, some carers having poor communication skills, carers not sufficiently valued and inadequate monitoring of home care contracts the Council has with providers.

“Agencies need specific training in dementia. They shouldn’t be allowed to tender for contracts if the staff are not trained”.

“Language barriers and communication barriers make it all the more difficult to engage with the service user”.

“We cannot get the type of home care that we need, other than from the Dementia Home Care Team”.

“The respect for and status of home support workers must be increased by society as a whole. They are central to the ethos of care in the community and many, many people are dependent on them for their health and well-being”.

Day activities

People expressed that current day care and the activities in residential settings could be improved, day care could be offered for longer hours and the activities available should be stimulating and maintain people’s functioning. There were also issues raised regarding access to day care and activities.

“We could use Heathlands day centre in different ways and providing different activities”.

“Other day centres need to offer longer days and weekends. The traditional 11 until 2.30pm is not long enough for carers to pursue an activity. Heathlands day centre is open 7 days a week”.

“Staff at Heathlands residential care home need more time to do activities with residents. Staff don’t have time at the moment to do this, as doing all the care aspects”.

“Need more opportunities to take people ‘personal’ shopping”.

“Day centre places are like gold dust”.

Resources

Under this theme of resources, issues such as capacity in the voluntary sector, in the CMHT OA and the Dementia Home Care Team arose. People told us these highly regarded services need to expand the amount of support they can offer. People were aware that the type of flexible home support offered by the Dementia Home Care Team was expensive, yet the quality of the service and outcomes for the people using the service were excellent.

“Need earlier referrals to Triple A, but we have capacity issues”.

“Finding new volunteers is hard”.

“Need more support workers in the CMHT OA”.

“The Dementia Home Care Team is flexible in the sense that if they do a visit, and a person needs more time, they are generally able to provide this. The team works in an outcomes-focused way, as opposed to being time and task bound. This means, however, that this service is substantially more expensive than normal home care”.

Range of respite available

Respite care was another theme that arose from the data. The people we spoke to felt there was not enough choice, availability or flexibility of respite care.

“The overnight respite service at Heathlands works well, but his needs to be offered 7 nights per week with an emergency bed available at all times that carers can self-refer to”.

“As we don’t have the ability to pre-book (a nursing respite bed), the person may be placed out of area, and go to different places on each occasion they have respite care. There is no continuity of care for the person”.

Training

Several issues came up which were themed as training issues. These included training and awareness raising for the wider workforce and clearer pathways of care. It was perceived that people not working directly with people with dementia were not very knowledgeable about the condition, yet it was important that they should have a basic understanding. Also, there were concerns about the referral process and clearer routes of diagnosis were identified as necessary.

“GP’s should refer to the CMHT OA for a diagnosis. GP’s only receive 2 hours of training on dementia. This is not enough to make a diagnosis”.

“The Dementia Home Care Team sometimes have older people with mental health problems referred to their service. This is inappropriate as it should just be people with dementia”.

The main themes from the analysis of the data to question 2 have been stated above. As well as these themes, specific areas of development were also raised from individuals and teams. These issues included poor transport, access to information, joined-up working, valuing carers and valuing home care staff.

3. What support and services do we need that we don't already have?

A wealth of data was generated in response to this question. People had clear ideas on where there were currently gaps in services or where existing support needed to be expanded. On analysis, 6 themes arose from the data.

Increased amount of flexible day support

People clearly identified that we needed a larger range of day support options, which are differentiated to meet people's needs. People at different stages of dementia need different types of support that is appropriate to their age and ability. However, in all day support options, the emphasis should be on people being involved in meaningful and stimulating activities and social contact.

"We need a drop-in centre specifically for people with dementia".

"Day care for active older adults with dementia run along the same lines as the Monday group for younger people with dementia (Triple A's group)".

"We need different day care provision for people in different stages of dementia. Current day centres need more activities going on. Need to get people more involved, take people out for the day. Could have different rooms for people in different stages of dementia".

"Need both individual support options and day centre options for people, so people have the choice of how to receive support".

"People need activities that are meaningful to them where they can still use their intelligence".

"(We need) a drop-in centre specifically for people with dementia".

Resources

The theme of resources was identified as a result of several ideas that concerned having more money to fund new support, having more affordable services or increase capacity in current provision. Some people wanted to see a befriending or buddying scheme, others expressed that there should be a high quality range of affordable residential care available. Increasing the capacity of psychology services, social work and having a GP with a special interest in dementia were also identified as ways to reinforce current support options.

"We need someone to lobby central government. For care in the community to be sustainable we need extra money. Care in the community is not a cheap option, but it's cheaper than long term care".

Care

This theme embraced carers' issues, continuity of care and personal care that people may need. 'Informal' carers need different kinds of support, people with dementia should have continuity of care and have access to the personal care they may require.

"We need support for social lives for carers".

“People need company. Having different carers, but ones they know, makes people feel safe”.

“More bathing and toe nail cutting services”.

Living arrangements

People identified supported accommodation as an area for development. This ranged from people having housing-related support in their own homes and improved availability of different kinds of sheltered housing, to having smaller residential units which offer a good range of activities for people.

“A different kind of sheltered housing is needed. We need more floating support and less warden-based schemes. Floating support is more flexible and meets people’s needs better than routine support from a warden”.

“Smaller (residential) homes on every estate so people who live on the estates can come in”.

“(We need) activity organisers and therapists in residential care homes, for example singing for well-being or wheelchair exercise classes”.

Awareness and access

Awareness of dementia was identified as a current gap, both with health and social care professionals and in the general population. With professionals, people felt more training should be available and it should be compulsory for certain groups. It was felt people did not know the signs and symptoms of dementia, and there was a stigma attached to dementia.

“When someone goes into a general ward in hospital, nobody on that ward is trained in dementia. For example, they will put the food down and go away, and have the medication in a little cup on the trolley. People end up dehydrated. They do not have the skills to deal with people with dementia”.

“Need more neighbourhood and community awareness, so people can ‘keep an eye on’ their neighbours”.

Access to dementia care and support services covered a range of issues. Areas that needed improvement included **information**. The points raised included information about benefits, general financial advice and information about what it means to have dementia and how this will impact on people’s lives. The overarching theme was having a person available to discuss the information, not just producing leaflets.

“Have a one stop shop for advice and information run in conjunction with Citizen’s Advice or the Tea House or a mobile one stop shop in local GP surgeries, for example, ‘come and meet your local health and social care professionals”.

“Someone to explain benefits to people...leaflets are no good. Need to train staff in benefits awareness”.

Under the theme of access, **responsive and flexible services** were seen as very important. Services need to be able to react and respond to the differing needs of people with dementia day by day or week by week.

“We need a better understanding of how to commission the care of people with dementia. We obviously need to look at time slots and costs, but we need to be more flexible. For example, a person can have 15 hours care a week, but only use 13 of those hours in one week and ‘bank’ 2 hours for the following week so they could plan an activity. It is currently too structured”.

“A personal care/domestic crisis response team...sometimes people only need a little bit of help to get by”.

Services and support being physically accessible to people with dementia was also highlighted. Provision of suitable **transport** was identified, as was providing **in-reach services**.

“Need specialist transport provision...it’s not easy to get someone with dementia on a bus...or get them off!”

Ways of working

The people we spoke to identified that current ways of working could be improved, which would support the service that was delivered. For example, having IT systems that worked across health and social care would facilitate the work of the CMHT OA. Pooled health and social care budgets would also enable services to provide more holistic support to people with dementia and their carers.

4. Within current resources, how could current services change to meet the needs of people with dementia?

In response to this question, people had clear ideas of how current services could adapt. There was an overarching theme of supporting, trusting and valuing staff, and *“making mental health more desirable to work in”*. As well as this, 5 other themes emerged as areas that could be changed within current resources.

Maximising use of existing resources

This was the strongest theme that came out of the interview data. People had clear ideas how **people, places and processes** could become more efficient and effective. The way people worked was seen as one way for current services to change.

“If you have the same amount of staff on duty, we could support domestic staff to have a dual role of domestic work and doing some caring as well”.

There were also many suggestions of how to use existing establishments and/or services in different ways. Improvements in IT systems between health and social care were also identified as a way to co-ordinate services more efficiently.

“Could use Downside in the evenings for younger people with dementia and have more appropriate activities, such as playing cards”.

“Heathlands day centre could be used more fully. It could be staffed by volunteers in the evenings”.

Enabling people to stay at home

There was an overall view that it is generally most appropriate to support people at home and enable people to stay in their own homes for as long as possible. People highlighted appropriate accommodation, emergency support, respite, support for carers and availability of day activities as contributing factors which help people to stay in their own homes.

“Could have more floating support instead of having wardens in sheltered accommodation. Floating support is more flexible, can be more proactive and specialised in dementia”.

“We need more independent supported living houses”.

“We could improve crisis management, and have referrals from carers and emergency respite”.

“Could be more creative with respite”.

Staff development

Under the theme of staff development, there were ideas around raising awareness of dementia amongst health and social care staff, skill sharing and more training opportunities to be available.

“There is currently 18 months to wait for specialist dementia courses. We need more trainers to deliver the training. Some staff could go on a ‘train the trainers’ course and deliver the training locally”.

“We need training for staff across the board...GP’s, independent providers and health and social care staff”.

Establishing new partnerships

Maximising the use of the voluntary sector was identified as a way to meet people’s needs within current resources. People felt that volunteers could supplement the work of paid staff at day centres. Also, new partnership opportunities were suggested, such as developing links with local further education providers to enable students to do work experience with people with dementia.

“Voluntary services are great and need to be tapped in to as much as possible”.

“We could get volunteers in...but CRB checking can be a barrier. Some people don’t want this”.

“We have a good link with Bracknell and Wokingham College and have work experience students. It encourages young people into the industry, and also gives young people the opportunity to get to know and have respect for older people”.

Improving transport

The people we spoke to had several ideas to improve transport for people with dementia, from having designated drivers at day centres, to making better use of existing transport and exploring new ways of funding transport.

“We could look at how much transport costs and how much it would cost for staff to pick people up. People would get a better service this way”.

“We could get local companies to provide a minibus and pay for the upkeep so that there are resources there to take people out and about”.

5. If you had a blank cheque book, what support and services would you like to see?

There were four main themes arising from the analysis of the data collected for this question. There was also an overarching approach that came out of the data, where people felt it was important to have **well-staffed, high quality services that addressed inequalities** and had a focus on **early intervention**.

How people live

The theme of ‘how people live’ was the strongest theme emerging from the interview and focus group data. The issues raised ranged from modernising the environment in existing residential provision and making it more ‘dementia friendly’, to having new, purpose built facilities which provide day support, respite and residential support for people in different stages of dementia.

“Safe and secure accommodation that is fit for purpose”.

“Small units set up in the community so people would be part of the community and not isolated in their own homes”.

“There is no suitable local residential support for younger people with dementia. (I would have) a purpose built place”.

“Use an existing sheltered accommodation scheme to provide homes for people with dementia, so people can remain independent yet get help when need be. There would be an upheaval initially, but it would be worth it in the long run. There would be more communal interaction and activities, so people wouldn’t have to go to day centres”.

To support people to maintain their independence and stay at home if they choose to, appropriate personal care and housing related support should be available.

“A good home care service from the external providers with all carers being trained properly in the basics as well as the more specialist aspects of dementia care”.

“People need the right level of support with their personal care as well as with their housing needs”.

Day support

Most people we spoke to wanted to improve all aspects of support available during the day for people with dementia and carers. People expressed a desire for improved day care and respite facilities, more support for carers and meaningful activities in the community for people with dementia.

“We need different day centres for all people with dementia...have different grades of day centres and this will support carers. For example, have ‘grade

1' day centres, which are for people who are over 65 and in good physical health, 'grade 2' for people over 65 with moderate physical health, and 'grade 3' for over 65 with poor physical health. We currently have provision for 'grade 3', but not 1 and 2".

"More proper respite...a 7 day complete break for carers".

"(We need) more activities in the community in general".

"Longer opening hours of existing day care provision".

Dementia awareness

With a blank cheque book, people would like to promote greater awareness and understanding of dementia, both with the general public and with health and social care staff.

"Need more training for carers, and more education about dementia in schools".

"Could have an 'ambassador for dementia' working with the college".

"More awareness for GP's so people can get help earlier".

Access

The final theme that arose in response to this question is that people would spend unlimited resources on improving access to services, including: improving **transport**; providing **information** in appropriate formats and access to **emergency support**.

"More individualised transport is needed, to enable the carer and cared for to do what they want to do".

"Less leaflets and more 'user guides' reflecting both health and social care's involvement in a person with dementia and their carer's journey".

"Improvements to crisis management...receiving referrals from carers and emergency respite".

6. How can we improve access to support for vulnerable groups?

We explored ideas around enabling access to services for groups who may experience barriers to accessing support, such as people with learning disabilities, people from Black and Minority Ethnic (BME) groups or younger people with dementia. Three main themes arose, detailed below.

Younger people with dementia

People felt that younger people with dementia needed to have specialist support in all aspects of their care. Also, it was expressed that staff needed training to understand some of the issues that were relevant to younger people with dementia.

"It is more difficult to support younger people with dementia. They have a greater understanding of what is going on and, as a result, seem to have more anger management issues".

“Need more support in the community for younger people with dementia”.

“Need some kind of residential care for younger people”.

Access

People felt there was a lot that could be done to improve access to all services for any person with dementia who needed those services. People said access to services could be improved by having **interpreters** and **culturally friendly diagnostic tools**, having more **information** available, combating **stigma**, systems to **gather informal information**, better **partnership working** and **improving pathways of care**.

“Have a short and snappy information sheet in different languages available widely, including in Polish supermarkets, places of worship and GP surgeries”.

“If people were more aware of signs and symptoms, then perhaps more people would access services”.

“Dementia is a very secretive condition, people do not want to admit to it. There is a lot of stigma surrounding it. We need to address this”.

“Word of mouth works well”.

“People have to be seen by a doctor first. If there is a blockage there, then it is very difficult for people to get access to services and support”.

Resources

People told us that they believed there to be a lack of resources and understanding around **BME** groups. **Carers** were also identified as experiencing barriers to accessing support, and that extra resource should be put into this area. A **one-stop shop** was suggested as a way to improve access, as was encouraging **supportive communities**.

“(With BME groups) there are language and cultural barriers, which can lead to difficulties in diagnosis and lack of appropriate information”.

“We need to find ways of targeting carers. People can be frightened and don’t seek help early enough”.

“We could have a liaison person to work with relatives, so they could inform them how to access support and information”.

“We could have all services and support in the same place. For example, in the new Healthspace, we could have support workers, the CAB and counsellors”.

“We need a service in the community that isn’t a service...more like a buddy scheme. We could have police community support officers involved. They could knock on doors. This would be an informal yet reassuring way to check on the well-being of older people”.

Views from carers

We asked carers about their experiences of caring for someone with dementia, and what support they felt was required. We also explored the support that was currently available, as well as how they would spend unlimited funding for dementia care. This last question was designed so we could explore people's aspirations for the future, unconstrained by the issue of resources.

1. Experiences of caring

The main theme that arose from this question was people's experiences of coping with becoming a carer and how this impacted on different aspects of their lives, for example becoming socially isolated because of caring responsibilities. The carers we interviewed all spoke of the importance of having **timely advice and information** about all the different aspects of becoming a carer. For most people, this was a new situation that they were ill-equipped and ill-informed to deal with.

"It would be useful to have access to somebody who could provide advice on the little tips and tricks that perhaps a professional might use in a similar situation".

"Carers are left to work out their own solutions".

The **psychological impact of becoming a carer** was also expressed as a difficulty.

"It is really difficult, and I have experienced a role reversal. It hurts when my wife can't do things for herself and it makes me feel sad all the time".

"I have had a most difficult time accepting that my husband has Alzheimer's and that because of this disease, his personality as well as his behaviours have changed completely".

2. What support do people with memory problems need?

When asking carers what support was needed for people with dementia, 2 main themes arose around day support and support from a range of services.

Day support

Carers felt that day support was crucial to the well-being of people with dementia. The day support available should consist of meaningful activities that stimulate people, whether this was provided in a day centre or as part of the local voluntary sector provision.

"More activities are needed so that people are not just sat doing nothing or watching TV".

"Activity groups like Triple A give people something to get up for and look forward to".

Support from a range of services

As well as having specialist support for people with dementia, support from other healthcare professionals was seen as very important. People with dementia may need services from a range of people, such as chiropodists, opticians, occupational

therapists and community psychiatric nurses. The idea of having a 'keyworker' role also emerged: having one dementia professional to oversee a person's care was seen as useful. Poor co-ordination of services was identified as an issue: *"The left hand seemingly unaware of the right hand's role!"*

"(People with memory problems need) their own personal, specially trained professional helper, who is able to deal with the everyday living problems which loss of memory brings, not only physically and socially, but also emotionally as well".

Other issues raised by individual carers included appropriate respite care, transport and advice on preventative measures that could be taken.

3. What support do carers need?

The carers we spoke to identified 4 main areas of support that they required. **Accessible information** once again was raised, as was **financial help and advice**, particularly for carers of younger people with dementia. **Respite** care was seen as crucial to give carers a break and **support for the whole family** was identified as an area for development.

"There are a lot of hidden costs associated with caring for someone with dementia. For example, (the person I care for) can use 5 tea bags to make a cup of tea...or food goes out of date, or the same items are repeatedly purchased".

"Need more respite that is easily available, flexible and free for the benefit of the carer".

"More respite spaces and weekly one night care beds are badly needed now. This would help carers keep going".

"No-one offered to help the children".

Individual carers also identified other issues such as having help with shopping, having 1:1 support and the idea of having a carers drop-in in a central location where carers could get support on all aspects of caring.

4. What are your views on the support currently available for people with memory problems?

Voluntary sector groups were viewed very favourably as a current support option. Carers told us that the activities offered were good for people with dementia, as well as being supportive towards carers. However, there were some aspects of current support that were seen as in need of improvement. **Day support**, particularly day centres, was seen as not offering long enough hours and as difficult to access. **Information about, and access to** help and support was identified as a barrier. The other main issue raised by several carers was **attitudes** to people with dementia.

"Help from voluntary organisations in our district is the mainstay of many carers and patients here. These organisations should be supported very

much more, but without interference by the local Council, so they can continue their excellent supporting role”.

“The current provision of day care does not permit a carer to have a full day out”.

“It is incredibly difficult for any of us to carers to find out what and from where help is available”.

“People with cancer get more help. I feel with Alzheimer’s they think you are old and only fit for the rubbish! Dad is young”.

Transport, respite care and continuity of care were also issues raised by individual carers as areas for development.

5. What are your views on the support currently available for carers?

In response to this question, many similar issues were raised as identified in the previous question: the benefit of **voluntary sector groups**, problems with **information, access and day care**. Two new themes arose; the quality of **home care** and the **wider range of help available**. Carers who had experience of the Dementia Home Care Team at the Council saw this as an excellent service. Issues were raised on help available from other professionals; carers expressed that GP’s need more training on dementia and that carers need more support to understand and cope with medical and behavioural problems associated with dementia. One carer had received support from a speech and language therapist, which they found very useful.

“The Bracknell Forest home support service has been excellent from my current experience. This could be extended to other services”.

6. If you had unlimited funding, what would you spend it on to best support people?

The carers we spoke to had many and varied ideas of how people could be supported if unlimited funding was available. Ideas included better transport, more respite, help with adapting homes, 1:1 training for carers, befriending for people with dementia, more better trained staff, improved day care, counselling for carers and people with dementia, specialised legal support, early diagnosis and a club house in Bracknell.

Views from people with dementia

People were asked an introductory question and were also given an opportunity to add other comments if they wished at the end of the interview, as well as the specific questions stated below.

- Can you tell me about yourself and your experiences with memory problems?
- What services or support do you currently get?
- If you could have any help that you needed to make your life easier, what would that be?

The people with dementia we spoke to were all currently receiving some kind of support and on the whole were happy with the support they were getting. This support ranged from sheltered housing, support from the CMHT for older adults and from Triple A. Three main themes arose from the data.

Informal care

A strong theme of informal care emerged from the data. People perceived this as the most important type of support they received. Everyone we spoke to emphasised the importance of having a support network, and how family and friends helped them to get on with day-to-day life, for example by taking them out shopping or providing meals.

“I am lucky as I have good support from family, friends and neighbours”.

Support in the community

People were also receiving most of their support in the community and this was highly valued. Meeting other people and socialising was regarded as very important, and voluntary sector groups such as Triple A's younger people with dementia group was a good way to meet other people and take part in activities.

“Triple A is good to get people out of the house”.

“I enjoy going out with Triple A as I can meet people”.

Maintaining a ‘normal’ life

The people we spoke to all wanted to retain as much independence as possible, doing everyday activities and having a good social network.

“I am caring, keen to keep active and young at heart for as long as possible, despite having memory problems”.

“I do a lot of what I like to do”.

Discussion and recommendations

In general, the services and support currently available were seen as working well, particularly the support offered by the CMHT for older adults, the Bracknell Forest Dementia Home Care Team, the day hospital, Heathlands respite and residential care and voluntary sector organisations. Certain aspects of how these services are provided were identified as being crucial in their effective delivery, namely: well-trained staff; good relationships between organisations; continuity of care; helping people to maintain independence and quality of life; working in a holistic, person-centred way and timely provision of advice and information. Issues around safeguarding people with dementia should also be a thread running through all aspects of dementia support.

- **Continue to build on successful services, and change and adapt support available as appropriate to meet people’s needs**
- **Continue to support and value the work of the voluntary sector, looking at new ways to work with the voluntary sector to improve people’s lives**
- **Encourage all providers of dementia support to access safeguarding training, and we will require all providers we contract with to sign up to the adult safeguarding policy and access safeguarding training**

People felt there was still room for improvement, expansion and opportunities to look at the ways existing resources were used to improve the support available to people with dementia, carers and families. Particular issues raised included the provision of appropriate home care, day support and the need to improve awareness of dementia amongst health and social care workers and in the general population.

- **Investigate opportunities for commissioning specialist dementia home care provider services**
- **Support current home care providers to increase staff skills and awareness of dementia**
- **Recruit staff to increase the capacity of our specialist home care**
- **Investigate how to improve day care options**
- **Investigate ways to increase people's awareness of dementia, both in the general population and in health and social care workers**

Supporting carers and their families was identified as being a crucial aspect of dementia support. 'Informal' care is highly valued by people with dementia, and it is vital that carers are well supported. There were many types of support identified, such as having a range of respite options, availability of emergency support and financial support.

- **Continue to support and value carers and their families, and involve carers and people using services in the development of new initiatives**
- **Investigate new opportunities for provision of a range of flexible respite care**
- **Increase awareness of who to contact in an emergency**
- **Be aware of the financial hardships families can face and promote benefits and financial advisory services**

Access to support was perceived as being a challenge. Access covered a range of issues, from lack of awareness and information about support, to getting timely access to support required and having the transport and finance to attend community based activities. Certain groups were also identified as having particular issues accessing appropriate support. These included BME groups, people with a learning disability and younger people with dementia. If support is not accessible, this can lead to people with dementia and their carers becoming socially isolated.

- **Address barriers to accessing support: information; timely support; transport and finances**
- **In partnership with health services, work towards tests for dementia that are appropriate for people from all backgrounds and ensure that dementia care is culturally sensitive**
- **Improve partnership working between learning disability and dementia services**
- **Expand the options for support for younger people with dementia**
- **Investigate the options for having a dementia care adviser role, who could be a single point of contact for people to access advice and support**

The importance of having supportive communities and having support available in community settings was a thread that ran through all the interview data. There were points raised concerning accommodation and housing related support needs, and having availability of suitable accommodation for people at different stages of dementia.

- **Wherever possible, make sure support is available in community settings and be designed to help people to maintain social contacts and a 'normal' life**
- **Work with housing providers and other teams within the Council to address accommodation needs of people with dementia**

Increasing resources for dementia care was seen as crucial, to develop and expand current services and to have support available for the increasing numbers of people with dementia over the coming years. There were also many ideas on how to maximise the potential of existing resources.

- **Work towards increasing the number of people volunteering in dementia care, for example, by making new partnerships with colleges**
- **Investigate opportunities for using existing resources in creative ways to meet people's needs**
- **Continue to invest in staff development and training**

Key points from analysis of survey data

- Generally, services and support currently available work well, and the aspects that make them work well should be integral to all future service provision
- The support available from the voluntary sector is highly regarded, and enables people to maintain independence and quality of life
- People working in dementia care should be aware of safeguarding issues
- Home care services need to effectively meet the needs of people with dementia
- People value the service provided by the Bracknell Forest in-house dementia home care team
- Day care options need to be varied, with longer hours, flexible to meet individual needs and with a range of stimulating and meaningful activities to be available
- The general public and health and social care workers need to be more aware of dementia
- A range of respite care options should be available
- People would like emergency support to be available
- Carers and families of people with dementia play a crucial role, and need to be well-supported, both emotionally and practically
- Some people experience financial worries, particularly families of younger people with dementia
- Access to support can sometimes be difficult. People may not know about available support, support may not be available when required and transport is a big challenge
- People from BME groups may not be receiving appropriate diagnoses or care
- People with learning disabilities are at a higher risk of developing dementia, and services need to be able to support people with complex needs
- Younger people with dementia should have age appropriate services
- There are accommodation and housing related support issues for people with dementia
- Statutory services could encourage people to volunteer and help provide care and support for people with dementia
- Existing resources could be used in new and creative ways
- The dedication and skill of staff is very important in providing effective care

2. Consultation

Ways we engaged with people to inform the commissioning strategy

Consultation (October 2008- January 2009)

- Consultation paper sent to people who expressed an interest after the qualitative needs analysis
- Events attended and facilitated discussion of consultation paper held
- People and groups who had not participated in the needs analysis identified and approached for feedback.

The findings from the qualitative needs analysis were summarised in a consultation paper. The consultation ran from 6th October 2008 until 12th January 2009. The consultation document, as well as summarising the key findings, incorporated other drivers behind the development of the commissioning strategy and invited people to comment on the proposed priorities for dementia support in Bracknell Forest.

Consultation Methodology

- Consultation paper developed and agreed with project team, Adult Social Care Management Team and Executive Member
- Feedback form developed
- Project team identified people who had not been involved in the qualitative needs analysis and agreed appropriate ways to approach and engage with these people
- Involvement in relevant events
- People who had expressed an interest in ongoing involvement after the qualitative needs analysis were sent a copy of the consultation paper for comment and input. Groups were approached again to ensure the consultation paper covered the issues that had been identified.

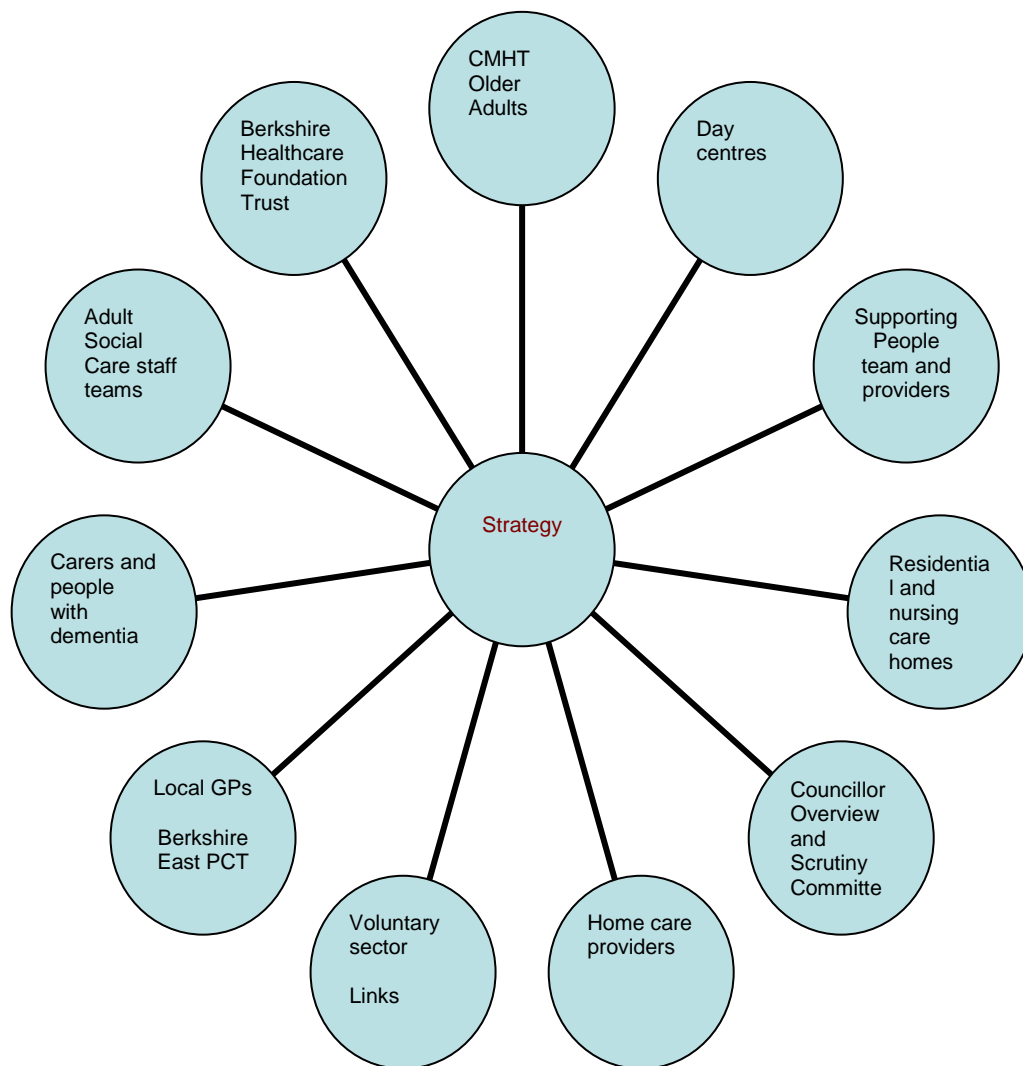
The feedback form was kept simple, with three questions being asked:

- Do you have any general comments you would like to make about what you have read here?
- Are there any important issues that you think are missing? If so, what are they?
- What do you think of our proposed priorities?

There were different ways people could engage with the consultation. The consultation paper was online, could be sent to people electronically or hard copies were widely available. There was a freepost address available for people to use when sending back their feedback forms, pre-paid and addressed envelopes and email drop box.

We also attended events, forums and staff meetings to engage with different groups of staff, partners, carers and people who use services to seek their views.

The figure below illustrates the range of groups and individuals we engaged in the consultation.



Findings

Overview

The consultation ran from October 2008 to January 2009. We received 45 completed feedback forms from our consultation paper during that time, and also spoke to many other people at events in the voluntary sector. A thematic analysis was employed to analyse the data.

Each question included on the feedback form was analysed individually, and themes and issues that related to more than one area were identified.

1. Do you have any general comments you would like to make about what you have read here?

From the analysis, people were generally very positive about the proposed priorities, and found the consultation paper clear and easy to read. The main themes that arose from the data were

- Making it happen
- Support available
- Carers issues
- Organisational aspects of dementia support.

Making it happen

Overall, the response to the consultation paper was very positive, with the majority of respondents in broad agreement with the content. People commented that it was well presented, reflected people's views and was easy to read. However, the issue was raised that the paper was very general, with no specific detail about how the proposed priorities were to be achieved.

"It is evident that relevant stakeholders have been consulted and more importantly, listened to, in respect of a dementia strategy for Bracknell. I believe it is essential that some of the priorities are addressed sooner rather than later".

"Easy to read and clear. But is it realistic? Who/where/how is it going to be implemented? How is it going to work? Will it be as positive in real life? Sounds promising, but there are some duplications and it needs to be tightened up/have more focus".

Support

The theme of what support and services were available also arose. This broad theme included access to support, which was sometimes problematic, and support for younger people with dementia. It was re-iterated that support available from the voluntary sector was highly valued, and that transport issues need to be addressed. Peer support and assistive technologies were identified as areas that had not been covered in the consultation paper.

"It was a voluntary support group that has given me most information towards available help. Social Services and Age Concern have since given us good support".

"Good neighbours, befriending and buddying scheme good for people who are isolated".

"Although younger people with dementia are mentioned more could be included re: work support".

"The consultation paper does not mention telecare".

Carers issues

Support for carers also emerged from the data. The support that carers need was clearly identified, and included emotional and practical support, respite, and training for carers. Overall, people felt carers support should be emphasised and strengthened.

“The role of dementia care adviser I feel could be a valuable one and could be expanded on to include a dementia carer support worker”.

“In the section ‘supporting carers’ there could be much more support when the patient is first diagnosed. The carers need someone to talk to, to learn what it is all going to mean. All through the illness there is no chance of any counselling for the carers (I know I tried). They desperately need to be able to talk and tell of things that are happening, and how to cope with them. I’m afraid a 1 hour session per month , although helpful, is not enough by a long way. Much of the emphasis is on the patient, but if it wasn’t for the carers, what would happen? And what about when the patient dies?”

“My concerns are over the specific issue of the very limited advice available to family carers when they are faced with the patient having specific symptoms and/or behaviour. The patients’ doctors respond to issues that may require direct medical intervention, if such treatment or medication is available. However, in circumstances when the patient exhibits a symptom or action that the doctors cannot overcome the carer has to deal with it on a daily, or even hourly, basis. Most family carers have not had previous experience and thus need help to allow them to cope. When the problem is to do with patient’s inability to carry out certain activities, such as with some domestic activity (washing, dressing, cooking, shopping etc) the professional care services can provide assistance and guidance to the family carer. But when the issue is the behaviour or action of the patient due to the declining mental processes, the aforementioned care services cannot help. Indeed the social workers and even CPN’s provide very limited help. The point often made is that because patients are individually so different the family carer has to try and find a solution that fits that patient. I acknowledge that no one solution will fit all patients. However, with all the professionals involved with dementia patients: doctors, nurses, dementia carers, hospital staff and care home staff, there must exist a wealth of experience and knowledge that could be put to good use. The family carers would be better served by being offered 6 suggested coping strategies than none”.

“I would like to see it made easier for carers to have a break by having more respite care places available. The process of getting a place in respite doesn’t seem easy and if you book in advance the general opinion seems to be that you cannot be sure this will happen, leaving carers frustrated and upset”.

Organisational aspects of dementia support

Models of care, joint working, safeguarding and equalities issues formed this theme. Guidance for how people should work with people with dementia was seen as lacking, joint working was believed to be the best way to meet people’s needs but was sometimes problematic and finally, appropriate support should be accessible regardless of ethnicity.

“Joint working and partnership is already in place to a degree, but not always working in practice. How will this change?”

“We need a continuation of safeguarding issues support”.

“Individualised dementia care needs support related to culture/age and preference. (This is) very much needed and valuable when in place”.

2. Are there any important issues that you think are missing? If so, what are they?

When responses to this question were analysed, several themes emerged from the data which emphasised and reinforced the findings from the first stage of the needs analysis, the strongest of which was carers support. Day activities, accommodation issues and ways of working also arose. There were also several new issues, as well as specific services and support identified as missing from the consultation paper. Also, the question regarding specific detail of how the priorities were to be achieved came up again.

Reinforcement of findings from first stage

There were several issues identified which reinforced the findings from the first stage of the consultation. Carers support was a key issue, and several aspects of this were identified including coping with challenging behaviour; access to information and support, for example through a carers' drop-in in the town centre; involvement of carers and acting on feedback; respite and financial advice.

"I need help with coping with behaviour problems".

"More information about dementia for the family. Information on basic health issues and when intervention should be addressed".

"Once a person has been diagnosed with dementia, their carer requires a package of information to guide them to accessible help and advice almost immediately".

"No mention of families and their involvement".

"Feedback from carers about services needs to be taken up. This process needs to be facilitated and then acted upon!"

"If possible, night carers should be available to support the spouse".

"I think the items under 'to promote economic well-being' should be given a higher priority. This would have a direct impact upon 'improving emotional well-being'. Generally, people seem to be ill-informed of the benefits available".

A choice of accessible and age and ability appropriate day activities was also reinforced, as was appropriate home support and residential and nursing care.

"Day centres run by trained carers are a boon to both the patient and carer alike. They provide stimulus for the first and respite to the latter- to both they provide mental and physical refreshment".

"Carers need practical support as well as emotional support, recognition and information".

"Nursing beds are very hard to come by".

Ways of working, such as partnership working and continuity of care, as well as the impact that new ideas around self-assessment and personalised budgets were identified.

“Need good joint working with health colleagues in particular, and others, to work with the risks involved”.

“Continuity of care is very important and needs emphasising in any planning”.

“How can self-assessment be made practical and applicable?”

“Direct payments can be a nightmare- can be an added responsibility/burden for the carer. Need more support with direct payments”.

Other issues that were mentioned by individuals that reinforced findings from the qualitative data analysis included increased awareness, especially in general hospital staff and GP's, resulting in earlier diagnosis. Transport once again was raised as a challenge.

New issues

Specialist occupational therapy (OT) provision was the largest theme of issues that were identified as missing from the consultation paper. This included aspects such as telecare and adaptations.

“There is no mention of telecare or specialist OT assessments, equipment or aids”.

There were also a two new issues mentioned by a small number of people. These were support for people with a diagnosis of dementia and sight or hearing loss, and the issue of medication calls.

“Need to have communication support for deaf people with dementia to access information”.

Implementation

From the analysis of responses to this question, the theme of how the proposed priorities were going to be achieved emerged again. Issues such as how realistic the goal of achieving the priorities is and funding for these changes were particularly concerning.

“Need actual concrete improvements in service that will take place...will improvements be seen on the ground by individuals and carers?”

3. What do you think of our proposed priorities?

Again, the main theme that arose was around making the priorities happen. In general, people agreed with the priorities, although how they would be implemented was questioned.

“Proposed priorities are very good- appear cohesive and wide-ranging and appropriate”.

“Lots of priorities- a bit woolly...how will it make a difference to me? How can we achieve them? Need a costed out, realistic action plan”.

“Difficult to actually make sense of the reality of these priorities. Timescales and achievable goals would make it easier to digest”.

Some people also identified areas they felt were most important for immediate action: support for carers; day activities; more support for voluntary sector; awareness and equality of access. There were also ideas identified by individuals, which included stage specific dementia care, emergency support and home care which reinforced the findings on which the consultation paper was developed.

Discussion and recommendations¹

Overall, respondents to the consultation paper gave positive feedback about the paper. People generally agreed with the proposed priorities. An ongoing theme emerging throughout the feedback was the lack of detail in the paper concerning how the priorities would be achieved.

- **Work with stakeholders to develop a detailed action plan on how and when the priorities will be achieved**

When asked to identify issues missing from the paper, three new issues arose. These were involvement of families and providing feedback on what is happening in dementia support and the impact of the new transforming adult social care agenda on people with dementia and their carers, provision of telecare and assistive technologies and the specialised concerns of people with dementia and another condition.

- **Implement a system within the Council of involving carers and people with dementia, as appropriate, in the development, monitoring and evaluation of dementia support and services, including the transforming adult social care agenda**
- **Enhanced provision of Telecare and assistive technologies to enable people with dementia to stay at home**
- **Specialist support to be available to people with multiple/complex diagnoses or sensory loss and dementia**

The findings from the qualitative needs analysis and the consultation have informed the Dementia Commissioning Strategy.

¹ Recommendations that duplicate those found in the qualitative needs analysis are not included again in this section.