The Dementia Support Service (DSS)

The Dementia Support Services help people with Dementia and their carers to live independently for as long as possible in the community by providing support to help them feel safe and informed about Dementia and the support available.

Derbyshire County Council, Derby City Council and the NHS Clinical Commissioning Groups (CCGs) consulted on the delivery of the Dementia Support Services in Derbyshire and Derby City so they could make informed decisions about how these services could be delivered going forward.

The Consultation

**When:** February and March 2016

**Focus:** The delivery of the Dementia Support Services in Derbyshire and Derby City.

**Target group:** The consultation was aimed at people who use these services, professionals involved with them and other people who live in Derby City and Derbyshire County.

**Aim:** The aim was to gather opinions about the current service but also any other ideas on how support could be provided to people with Dementia and their carers.

**Methodology:** The consultation involved a paper survey, an online survey, consultation focus groups and attending existing groups to gather feedback.

**Groups attended:** 4 specifically organised focus groups, Dementia Action Forum, Hardy Group, Derbyshire Dementia Action Alliance, SEWA – Indian Community Centre, Max Road Sheltered Housing, Mickleover Methodist Church, Eborn House, Leyland Estate, Alvaston Methodist Church.

Survey

The survey was available to be completed between February and March. In that time, there were 217 completed surveys submitted (a combination of online and paper postal surveys).

This included:

- 11 People with Dementia
- 61 Carers
- 62 Health and Social Care Professionals
- 73 who selected Other
- 10 left this question blank

There was an even split between carers or people with Dementia who completed the survey from Derbyshire (51%) and Derby City (49%).

Where the carers and people with Dementia who completed the survey lived.
What types of Dementia Support do you think are most valuable?

For all responses, Dementia Advice and Education was highlighted as the most valuable followed by Peer Support. Advocacy was scored as the least valuable.

The following were scored as most valuable:

- Responses from People with Dementia - Advice and Education and Group Activities
- Responses from Carers and ‘Others’- Advice and Education and Peer Support
- Responses from Health and Social Care Professionals – Advice and Education, Peer Support and Advocacy

“Peer support is the most valuable...to spend time with other people going through the same thing.” - Carer, Derby City

Key for graph
1 - Peer Support
2 - Dementia Advice/Education
3 - Benefits/Legal/Housing Advice
4 - Raising Awareness
5 - Group Activities
6 - Advocacy

Which of these venues would you be most comfortable in accessing support?

The most popular responses to this question were community hall, community care centre and cafes. See the graph below for all responses.

Other suggested venues that were not included in the survey were: church rooms, people’s homes, care/nursing homes and all hospital settings.

Some of the characteristics of venues that were highlighted as important to people with Dementia and their carers were:

Accessibility
Good public transport links
Parking
Disabled Access
Which ways of receiving support would be most useful to help people with Dementia and their carers?

Group face to face support (63%) and individual face to face support (71%) were selected by all groups as the support which is most suitable for people with Dementia.

Responses from People with Dementia themselves highlighted only face to face support and instant messaging as useful.

Similar for People with Dementia, Group Face to face support and Individual face to face support was selected as useful for carers.

However, in the case of carers, a much wider source of support was selected as useful; Website (62%), Telephone (64%) and Email (56%).

This trend was matched by the answers from carers themselves with individual face to face support being selected most by carers (74%), followed by group support (59%), telephone (56%), website (52%) and email (46%).

When would the following types of Dementia Support be of most benefit?

All types of support was selected as being most useful in week day times for both people with Dementia and carers.

Almost half (45%) of respondents selected that peer support would be useful at weekends as well as group activities (40%) and raising awareness (37%).

38% of carers would value peer support at weekends and 34% would benefit from peer support in evenings.

“Being a working carer, access to things in evening and weekend would be beneficial” – Carer, Derby City

The free text responses to this question included highlighting that some people with Dementia sometimes have difficulty accessing things early in the morning and in the evenings, as well as the importance of having service provision at a mixture of times and days. Others stated that there is not enough provision in evenings, at weekends and over holiday periods. The importance of having support and provision for carers in the evenings was also highlighted.

“Support in the evenings or at weekends, sometimes older people with dementia don't see anyone at these times” – Registered Nurse
The Dementia Advisor role is needed to:

- Explain options of what support is available and signpost to other services (explain to families as well as the person with Dementia and immediate carer)
- Help navigate the health and social care system and interpret health and social care language/jargon by using plain language
- Give guidance and support for self-funders
- Support younger people with Dementia to stay at work
- Empower carers to make informed decisions
- Form partnerships with other organisations to improve capacity of the wider community to support people
- Signpost to other health services such as podiatry, dietician, dentist etc.
- Provide coping strategies, support with challenging behaviour and provide strategies to help deal with people with Dementia in denial.

Practical support

Practical support and advice is needed on things such as:
Benefits/disabled badges/form filling/power of attorney/finances/Social services/legal support/council tax/pension/utility tariffs/equipment/assistive technology/housing

Knowledgable staff

The Dementia Advisors need to:

- Be knowledgeable and give clear advice – they need knowledge about all types and stages of Dementia
- Be proactive – highlight emergency care plans/contact card/contingency plans
- Give tailored information – knowledge of individual’s needs and knowledge of what is available in the local area.
- Adapt as people’s needs vary over time
- Support people with Dementia and their carers to make their home Dementia Friendly

There was a wealth of feedback on the service needing to be accessible. Information provision needs to be easy to obtain and the groups/activities need to be easy to access.

“Signposting to the wide range of support is very important as there is a lot of support and activities available if you know where to look” – Carer, Erewash

 “…if you are worried about benefits or housing you can’t focus on learning about diagnosis or general advice on the condition…” – Social Care Professional, Derbyshire

“Face to face is the best way to get information”

“Online support is ineffective for many people who either do not have computers or lack the confidence to use them” – Carer, Derby City

The service needs to:

Promote the service in a wide variety of ways
Be accessible and easily available and give practical advice
Provide a follow up call and leave an open door if people don’t want to engage initially.
Provide a phone call monthly to check that people are coping
Provide a pack of information/contact details/resources
One phone number/helpline
Continue support when people with Dementia are in hospitals & care homes - having a familiar face is important for people with Dementia
Use a variety of communication methods – including written/postal as not everyone is computer literate. Face to face is the best method.
Provide more information/signposting at GP surgeries and hospitals
Work with ethnic minority groups – have volunteers who speak different languages
Ensure information and advice varies over time and age
There was specific feedback and suggestions around the provision of groups for people with Dementia and their carers in the community.

**Comments on support groups**

The following were highlighted as valuable:
- Meeting people/ Making friends
- Getting out
- Befriending
- Peer support groups
- Social/Group Activities

The highlighted benefits/advantages of support groups for carers were:
- Carers learn from each other – problem solving – shared learning and networking is valuable
- Carers would be isolated without peer support
- A lot of carers would prefer to receive information from DSS instead of health professionals
- It is good to have Dementia specific carers groups

Support groups needs to:
- Be promoted widely
- Be accessible geographically, regular and timely.
- Be on bus route
- Consider where the cared for will go when care has support
- Have a range of options – not one size fits all.
- Support end of life as well.
- Support in and out of the home
- Give carers the opportunity to meet people in local area

The DSS should:
- Support people to set up their own groups to run independently
- Advertise groups in the hospital

**Activities were rated positively in the consultation**

Activity groups need:
- More activities with bus for outings
- To consider physical health as well as mental
- A forum to find out about activities for example holidays for carers
- To be provided at mixed times day/evening
- To consider transport
- To consider physical activities too

Suggested Activities or existing activities with positive feedback:
- Volunteers to take the person living with Dementia out for walks
- Community based sessions e.g. swimming
- More intergenerational learning to improve acceptance
- Courses e.g. computers, photography
- Lunch clubs
- Life History Café in Ashbourne
- Gardening
- Singing groups
- Holidays for the carers with cared-for
- Hardy group
- Trips out/Coach Trips

“Group activities make people feel uplifted and included. There is lots of fun and laughter and everyone makes each other very welcome” – Dementia Friend

**Information for carers was also highlighted as important**

- Information sessions should include telecare
- Training for carers is important (but needs to be well promoted.)
- Courses can link and lead on to other less formal support groups
- Carers need further courses later on as disease progresses (e.g. managing behaviour) – different phases not only at diagnosis
- Greater education about the specific behaviours that will come from specific types of Dementia is needed
- All courses should give a file of information that you can refer back to later.
- DSS and hospitals should link with education providers
- Information for ethnic minority groups courses are needed

“It’s good to meet other carers face to face” – Carer, High Peak

“The most important thing to me is meeting other carers at the carer support group and sharing problems.” – Carer, Derby City

This information has been used to shape the Dementia Support Services going forward to ensure consistency of local provision across Derbyshire and Derby City.
Although the main purpose of the consultation was to collect ideas and feedback on Dementia Support services, we also received some valuable feedback about other services or aspects of support for people with Dementia and their carers. The NHS Clinical Commissioning Groups and local authorities will consider this feedback when progressing with their future planning.

### Raising Awareness

Raising Awareness of Dementia amongst professionals and the public was a key theme in the consultation. The following was suggested as being needed:

- More Dementia friends training and Safe Places to raise the profile in the community
- Dementia Friends Sessions for people with Learning Disabilities
- Dementia Friends training for families involving all generations
- Awareness raising of young carers
- Awareness raising of Dementia in schools – services need to link in with education
- Awareness raising in health services – key routes for access to services
- Dementia friendly services in the community e.g. opticians, dentists etc.
- More Dementia training for professionals in health and social care services

### Education

The benefit of education in Dementia that covers a wide-range of topics was highlighted.

The Living Well Programme received positive feedback. Developments that were suggested for Living Well Courses:

- Evening courses
- Option for shorter courses
- Courses in different languages
- A course after diagnosis (e.g. what is Dementia) and then also offer a course for later stages of Dementia

“The Living Well course was excellent – they covered a huge range of topics and I often refer to the information they provided”

Not all people had knowledge of the education courses for carers so promotion of these courses needs considering.

A lot of information is online but this is not accessible to everybody.

### Suggestions for future service improvements/developments

The following was highlighted as a need by people completing the consultation:

- More befriending support and sitting services particularly in care homes.
- Timely diagnosis for people with Dementia particularly for people with learning disabilities.
- Some services require a ‘diagnosis’ to access them – this should be for everyone with symptoms.
- More appropriate telecare advice and options
- Raising awareness of the carers' emergency contact card.
- More information and support choosing quality services including care homes.
- A pro-active service that links into hospital and care homes
- Easy read tools to work with people with Learning Disabilities to understand Dementia
- More Dementia friendly sport
- Overnight support
- More support based in GP surgeries
- More emphasis on physical well-being: Regular MOT checks at GP or medical centre
- Nutritional advice for people living with Dementia
- Shared Lives for older people - particularly in the evenings and weekend
- Greater support around advance care planning for people who are in the early stages to gain their involvement in the future.

We would like to thank everybody that contributed to the consultation for helping us shape the new Dementia Support Services and providing us with other feedback on support for people with Dementia and their carers in Derbyshire and Derby City.