

Carers in Hertfordshire Dementia Strategy Refresh Report 2019

Carers in Hertfordshire provides advice, information and support to unpaid carers - people looking after someone who is elderly, disabled, has a physical or mental illness or who misuses drugs or alcohol.

Ensuring Hertfordshire's carers are identified, supported and stay well, is at the heart of our work. We give carers a voice together with providing them with opportunities to meet other carers. We also enable carers to share their views or experiences with those providing or planning health and social care services in Hertfordshire.

At the time of writing this report we have 4117 Dementia carers and 143 Young Onset Dementia carers registered on the Carers in Hertfordshire's database. All these carers were given an opportunity to have their say about what is important to them and the person that they care for as well as what they think should be included in the next Dementia Strategy for Hertfordshire. To enable people to engage in a way that suited their needs, we used a variety of different methods over a 5-month period:

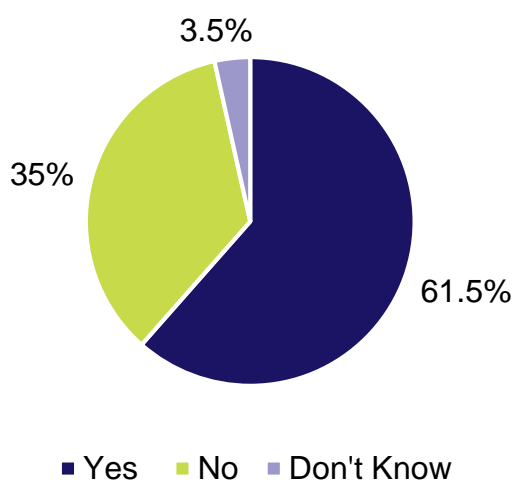
- Dementia Forums in Bishops Stortford and Hatfield
- Young Onset Dementia Forum in Hatfield
- A Dementia Strategy specific workshop in Hemel Hempstead
- Paper survey
- Electronic survey
- Telephone Conversations

The total numbers of carers who have contributed is 132.

Survey feedback:

Below are the questions that were asked in the survey, together with a summary of the most common responses.

1. Did the person you care for receive their diagnosis from the Early Memory Diagnosis and Support Service EMDASS?



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2. Please tell us about your experience of the EMDASS service?

The majority of carers found the service to be very efficient with caring, helpful staff. Carers feel that home assessments were ideal for the person receiving the diagnosis.

Some carers raised issues with the service, for example:

- Only received diagnosis, no other support
- Very little information
- Consultation very short
- No follow up appointment/further support
- All good until discharged to GP

3. When the person you care for was diagnosed, where did you turn for help and advice?

Carers mainly turned to:

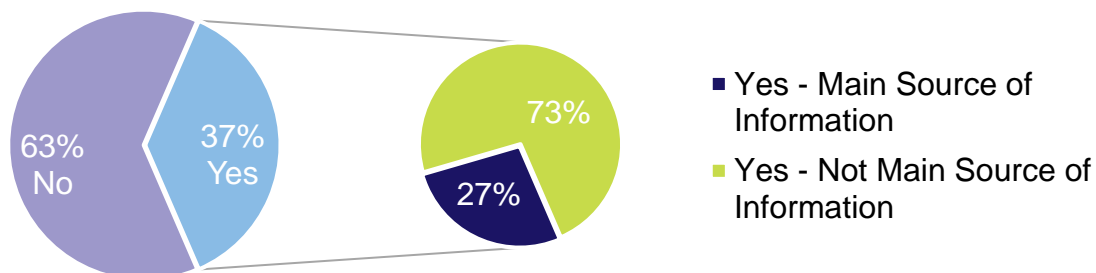
- Family and Friends
- Alzheimer's Society
- Carers in Hertfordshire
- GP
- EMDASS Team

Others mentioned Herts help, Admiral Nurses, Older Peoples Mental Health Team (HPFT), Carers Champion, Age UK Hertfordshire and Crossroads

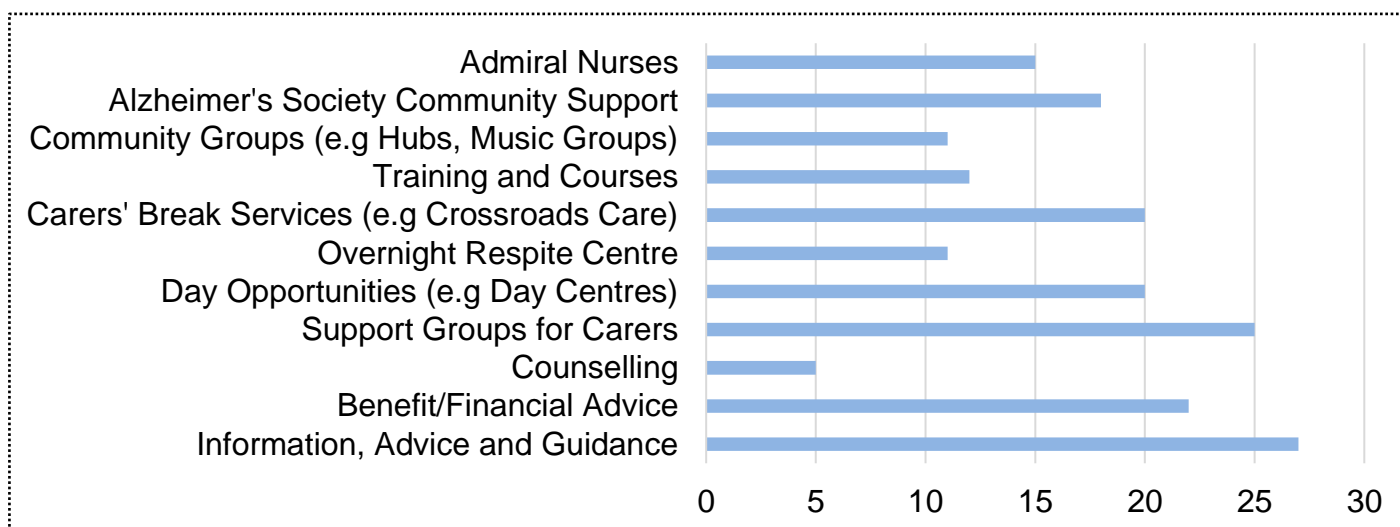
4. If you had a friend who had just been diagnosed with dementia, what would you advise them to do?

- Get into the system as soon as possible so people know you are caring
- Not to expect much support from the statutory or voluntary sectors
- Sort out Lasting Power of Attorney & wills as soon as possible
- Contact Age UK, Carers in Hertfordshire, Alzheimer's Society and Herts help
- Visit your GP

5. Have you used the internet to find out about services and support for yourself or the person you care for?



6. What services have you used?



7. What do you think are the most important things that help you and the person you care for to live independently in your community?

- Support for carers
- Time off from caring
- Respite care including overnight breaks as well as regular day care
- A point of contact

Other things that were important to carers included Crossroads Care, provision of regular monitoring and advice for each individual, good quality/reliable care agencies, friends and family, correct medication, home visits by Older Peoples Mental Health Team.

8. What can be done to help you better plan for the future?

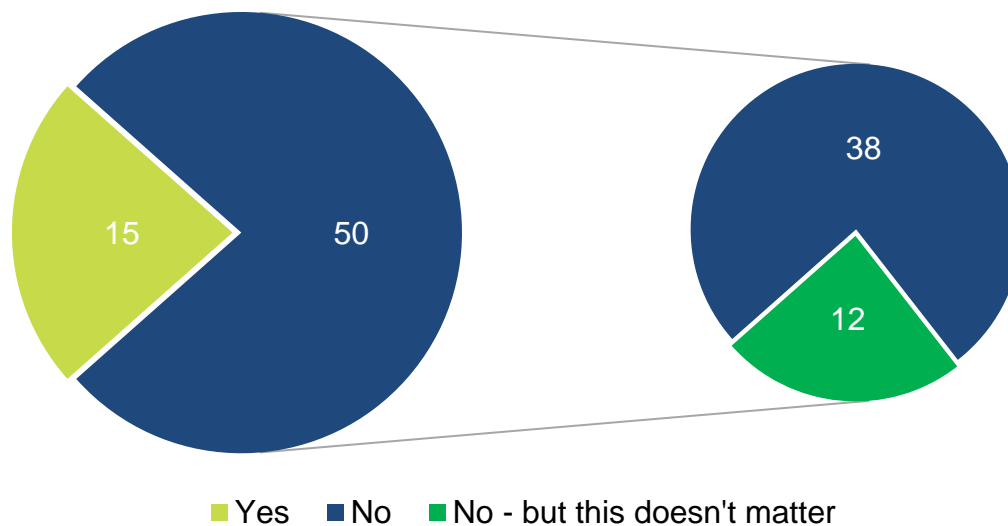
Regular breaks, including overnight respite were a high priority for carers allowing them time to even think beyond that day or even that hour. Other important support to help plan for the future included:

- Knowing how to access support in a crisis
- A contact person – to discuss, advise and plan with someone who knows the person with Dementia and the carer
- Regular reviews of the person with Dementia to reduce emergencies and monitor medication and their health and wellbeing
- Proactive social services – more support around planning for the future and what the options available are
- Financial planning support
- Admiral nurses
- Better advice and support earlier
- Better access to specialist doctors/consultants

9. Have you had to give up work to care for someone with Dementia?

- Majority of people were retired, but 14 people had given up or reduced work due to their caring role

10. Do you feel like you have a life outside of your caring role?



11. Do you think that your community is Dementia Friendly?

The majority thought that some or parts most of their community were Dementia Friendly.

12. What is the hardest thing about caring for someone with Dementia?

The most common themes here were isolation and loneliness, as well as a lack of sleep, alongside the stress of becoming responsible for everything.

NHS research into loneliness states that: Substantial evidence now indicates that individuals lacking social connections (both objective and subjective social isolation) are at risk for premature mortality.

Carers UK states: Right now, too many carers don't know where to turn for help. And too many are struggling alone because there just isn't adequate financial and practical support available. Our latest research report shows that 8 out of 10 carers have felt lonely or socially isolated as a result of their caring role.

Other hard things about caring for someone included 24/7 caring, physical and emotional stress, physical abuse, challenging behaviour, financial pressures, lack of information, not knowing how to get help and knowing it is only going to get harder.

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13. Any other comments

Carers also felt that there is a need for more funding for quality care, more rigorous checks on care agencies, social services needs to provide more support including a named worker, more day opportunities for the later stages of Dementia, good quality care homes, help with transport and help/education for children to understand the illness.



Forums and workshop feedback:

The forums and workshops that were held, as well as the telephone conversations with carers focused on the previous strategy and 5 key themes concentrating mainly on theme 4; supporting carers of people with Dementia (we did not discuss theme 6). Each theme is summarised below:

Theme 1 – Enabling equal, timely access to diagnosis and support:

Carers expressed that it was very important for the person receiving the diagnosis to be in the right environment for them, whether this be at home, at the GP surgery or at a specialist diagnosis clinic. The appointment should not be rushed, and a follow up appointment is essential for the carer and the person receiving the diagnosis to be able to ask questions and get the support, information and advice they need. The pathway for diagnosis should be clear, and explained before the appointments along with clear information of what will happen next.

Theme 2 – Promoting health and wellbeing

This Theme was important to carers, especially their own health and wellbeing, as they felt that they often neglected themselves due to their caring responsibilities; not exercising, eating poorly, a lack of sleep and not attending to their own medical needs. For carers to be able to achieve this they would need more support e.g. carers breaks, sitting services, day opportunities, overnight respite.

Carers stated that access to counselling to help them through the journey of caring would have been valuable – this support and offer should be in a variety of formats as one size does not fit all. Support for the carer around long-term planning would also enable both the person and the carer to promote health and wellbeing.

Theme 3 – Developing Dementia Friendly communities

The feedback around the importance of this was mixed, some saying that their community was friendly but not others. General feedback was that communities need to be ‘friendly’ not Dementia friendly. They often find that the use of the word ‘dementia’ in groups, activities etc actually discourages the person with Dementia from attending.

Some felt that Dementia Awareness week could be used more effectively in the wider community to encourage whole communities to think, and be proactive to, people with Dementia.

Theme 4 – Supporting carers of people with Dementia

Carry on caring if they want:

Carers feel that they have no choice in carrying on caring. The current social work support and practice does not always support the carers if they no longer want to ‘carry on caring’, with an example of this including carers being informed that they cannot access full time residential care until they have had a sufficient full package of care at home, even if this is not what they want. Carers would like to see more support in this area, better long term planning and more practical and emotional support around these major decisions.

Work if they want to:

Carers said that there are a number of barriers to this, one being the financial aspect of having to pay for additional care, and that the provision for day opportunities is generally 10am-3pm, not allowing them to work a full day. There is also a lack of transport to the venues running the day opportunities, causing another barrier for people to work.

They also feel that employers do not always understand their situation and that the social work support around this is not there.

Have a life outside caring:

This has mixed responses, mainly due to where the family are on the Dementia journey. Most carers at the beginning find that things are not too difficult and that they are able to have a life, but it becomes increasingly difficult as the person with Dementia deteriorates. Carers felt that there is a lack of support and services for the later stages of Dementia therefore preventing them from having a life outside of their caring role.

Staying fit and healthy and be safe:

Being safe was one of the most important things to carers, keeping themselves safe when behaviours become challenging as well as keeping the person they care for safe at all times. Carers did not know how to access support when they felt unsafe.

Carers stated that keeping healthy becomes one of the least important things with them, often not even attending medical appointments. This fits with data from the 2018 survey of Hertfordshire Carers where 39% say they postpone treatments because of their inability to leave the person for whom they care as well as 46% of carers having neglected their own health and 28.5% have not made/kept appointments with a health professional.

Good quality information when they need it:

Carers currently feel that there is a large amount of information and support in Hertfordshire but that it is impossible to navigate – carers did not want a pile of leaflets from each organisation, they want an easy to navigate booklet with all the information they need in it. A fridge magnet with emergency contact numbers was also mentioned a few times as it would be accessible when needed.

Carers said that they want practical and emotional support and more training around how to deliver the care to the person with Dementia. This is more important to them than coffee mornings and activity groups that they can attend.

Feel respected as carers/partners in care:

Being included in the person with Dementia's care plans, appointments, assessments and decision making meetings is essential to the carers and their families but currently, carers felt that they were not always included and definitely did not feel like a partner in care. The carers said that they did not understand their right to be involved or the process.

Carers would like more opportunities to meet with service providers/commissioners to hear about future plans and ideas before services are changed or new services are put in place.

Theme 5 - Preventing and responding to crisis

Carers who had been supported by an Admiral Nurse felt that they had been supported through a difficult stage and had access to other crisis support that they were unaware of. They felt that the Admiral Nurse had been invaluable to them and their own health and wellbeing.

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Other carers seem unaware of what help and support is available for them when situations become challenging. Some of the carers had used the crisis support team but had only been able to access via emergency services. Carers felt that if they had been aware of the services, they would have accessed it earlier and not been in such a crisis.

Crisis prevention is essential for carers. Most feel that more long- term planning and support would prevent crisis but that this often gets missed as the carer and the person you care for are not regularly reviewed.

Carers said that these vital services need to be accessible to all when they need it and with easy referral pathways.

Summary

The themes of the previous Dementia strategy 2015-19 are still relevant and important to the Dementia carers that we engaged with. Under each theme, carers feel that there should be more information about how the work is going to be achieved, who is responsible and how it is going to be measured. A clear time line of how and when the work is going to be completed is also needed, as well as information on how the carers can be involved.

Carers felt that there should be public documents reporting on the progress of the strategy and consultation during the lifetime of the strategy. Looking and evaluating a strategy at the end did not feel sufficient to the carers as it was too late to influence change and make progress. They also felt that they didn't know if anything had been achieved during the last strategy as there were no accompanying documents when reviewing it.



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