



Signposting Support for Dementia Service Users & Carers - Update July 2019

Background

In April 2019, Healthwatch North East Lincolnshire (HWNEL) conducted a study of signposting and support for dementia services in North East Lincolnshire (See Above), with specific emphasis on information given by Pharmacies. Due to the results HWNEL undertook a further mystery shop event of the same nature in community venues within North East Lincolnshire. This would provide us with further insight as to what information, advice and guidance is available to the public regarding dementia, within a person's own community and if this information is readily available.

This report will examine the way in which members of the public who are living with the effects of dementia are accessing advice, support and information through their local community venues. It will aim to highlight good practice, identify areas for improvement and offer recommendations. This report will explain the way in which HWNEL undertook research on this topic and our findings, discuss the issues identified, offer recommendations for improvement and outline our next steps within this subject.

Healthwatch North East Lincolnshire used five volunteers to operate a 'mystery shopper' style research project. The 'mystery shopper' method is where a person visits a service provider anonymously in order to assess the quality of the services. This involved our team entering local community venues without announcing that they are from Healthwatch North East Lincolnshire, and requesting information and advice regarding dementia and caring for someone with dementia. The aim of this approach was to gain a realistic insight as to the information, advice and support that was being offered to service users who are living with

the effects of dementia and their carers and relatives. Our volunteers and staff members anonymously visited 20 community venues across North East Lincolnshire, and explained to the staff that they had a spouse/relative/friend that had recently been diagnosed with dementia. Our team then recorded whether or not they were given further verbal advice about dementia, verbal advice about being a carer, or were signposted to any other local services. Our team also provided a brief summary of their visit, including any other significant information about their visit.

What is a Community Venue?

A Community venue is a public location where members of a community tend to gather for group activities, social support, public information, and other purposes. On this basis, Healthwatch NEL selected 20 community venues around North East Lincolnshire to mystery shop. The community venues that were visited by our mystery shoppers are:

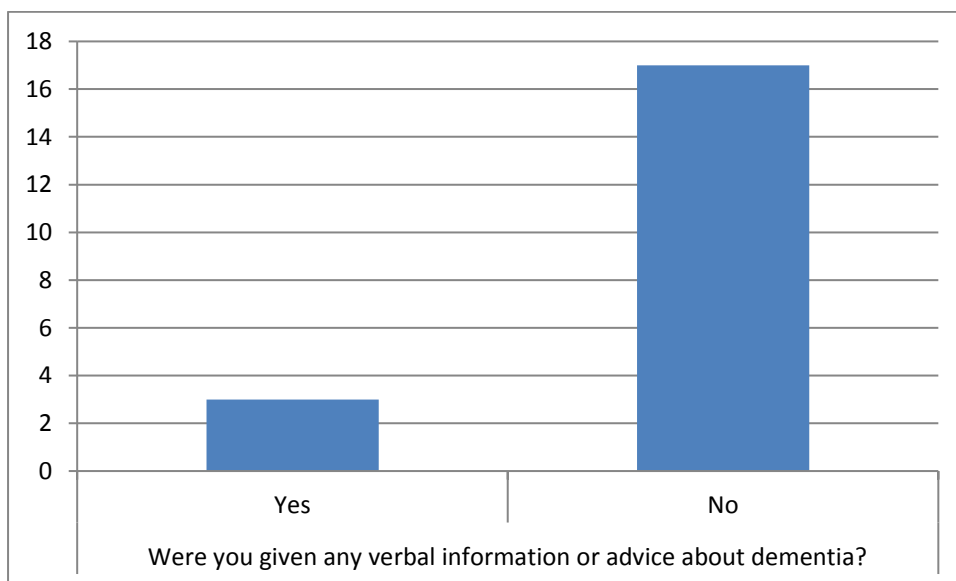
1. Scartho Library
2. Centre 4 Limited
3. Cleethorpes Library
4. Reynolds Family Hub
5. Highgate Family Hub
6. East Marsh Family Hub
7. Central Family Hub
8. Immingham Family Hub
9. Broadway Family Hub
10. Riverside family Hub
11. Nunsthorpe Family Hub
12. Scartho Family Hub
13. West Marsh Family Hub
14. Curzon Health and Wellbeing Centre

15. Your Place Community Centre
16. Annie Chapple Centre
17. Scartho Village Community Centre
18. West Marsh Community Centre
19. Val Waterhouse Centre
20. Grimsby Neighbourhood Centre

Data analysis

Healthwatch North East Lincolnshire visited 20 community venues across North East Lincolnshire.

Were you given any verbal information or advice about dementia?



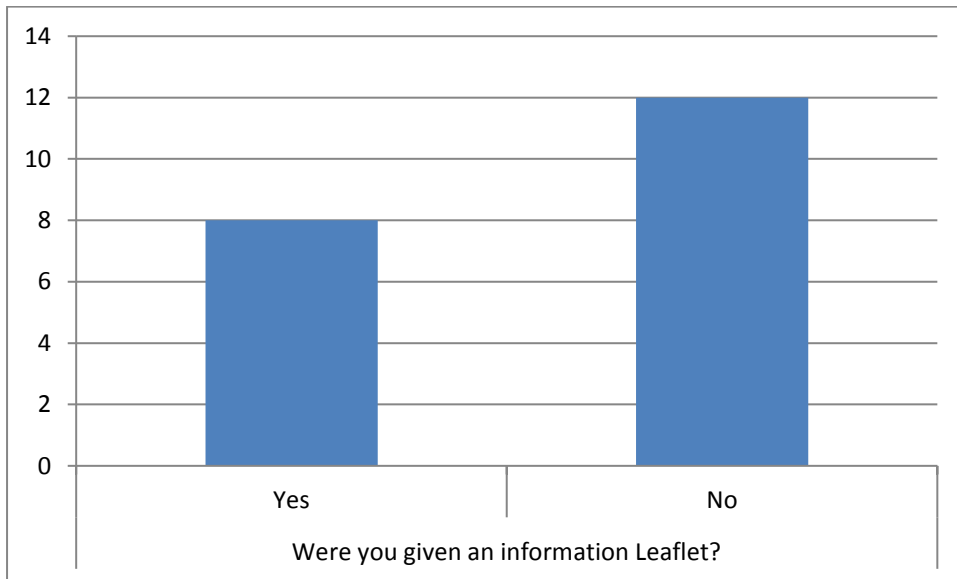
Only 3 of our mystery shoppers were given verbal information or advice about dementia. Our Team of Mystery Shoppers commented:

“They have a team who are available to give help and advice on all possible situations for you.”

“If I was genuinely shopping for help in these circumstances, this would be excellent.”

The remaining 17 mystery shoppers were not given any verbal information or advice about dementia.

Were you given an information leaflet?



Only 8 out of 20 venues gave out an information leaflet to our mystery shoppers.

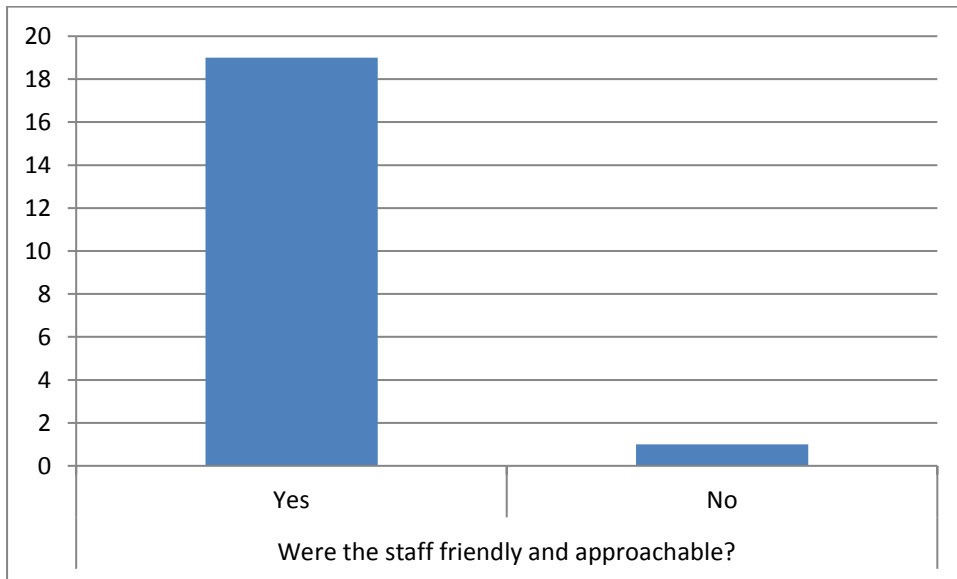
“They did not direct me to the leaflet carousel which I missed on entry but noticed it on exit. It had three directly relevant leaflets on Dementia.”

“Very comprehensive leaflets with all information needed in a simple format.”

“I was offered a large file to look through which held various leaflets and guidance in which I found several organisations to contact.”

The remaining 12 were predominantly sure start children’s centres, who all stated they only deal with 0-19 year olds, and so did not have any information available. The Dementia Action Alliance aimed to ensure that North East Lincolnshire became dementia friendly by the 31st March 2017. This included libraries, public facility, hairdressers, shops, post offices and community centres . The aim was to ensure they are dementia aware and supportive of those with dementia and their carers as this will provide wellbeing and preventative benefits. Additionally, the dementia strategy group and dementia action alliance were set to raise awareness of the support and services available to those with dementia and their carers at different stages of the dementia journey. The dementia lead were also actioned to ensure robust partnership working to promote each others services and support and the sharing of information (ie: leaflets) across the full range of organisations and agencies.

Were the staff friendly and approachable?



Our mystery shoppers found the majority of staff members they spoke with in community venues to be friendly and approachable. With some comments including:

“I was treated with kindness and empathy.”

“The staff were friendly and helpful.”

“Staff were very keen to help.”

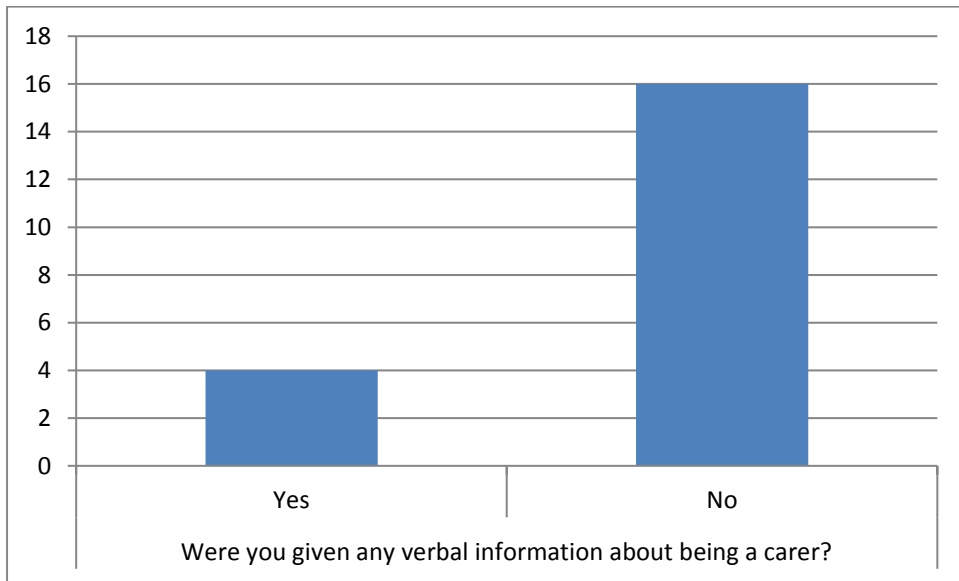
“The staff were friendly, approachable and made contact with me as soon as I walked up to the front desk.”

“If I was a genuine service user asking for information I would have very much appreciated the time and opportunity I was given to talk about my concerns and join in activities for respite.”

However, one mystery shopper stated:

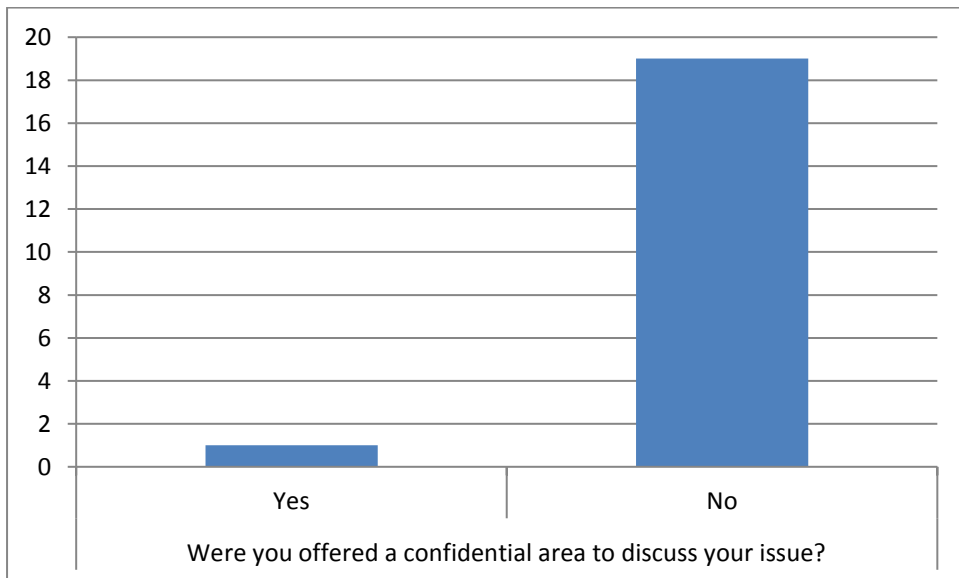
“Staff were not very receptive and weren’t really interested. They had no information, leaflets or advice to give me.”

Were you given any verbal information or advice about being a carer?



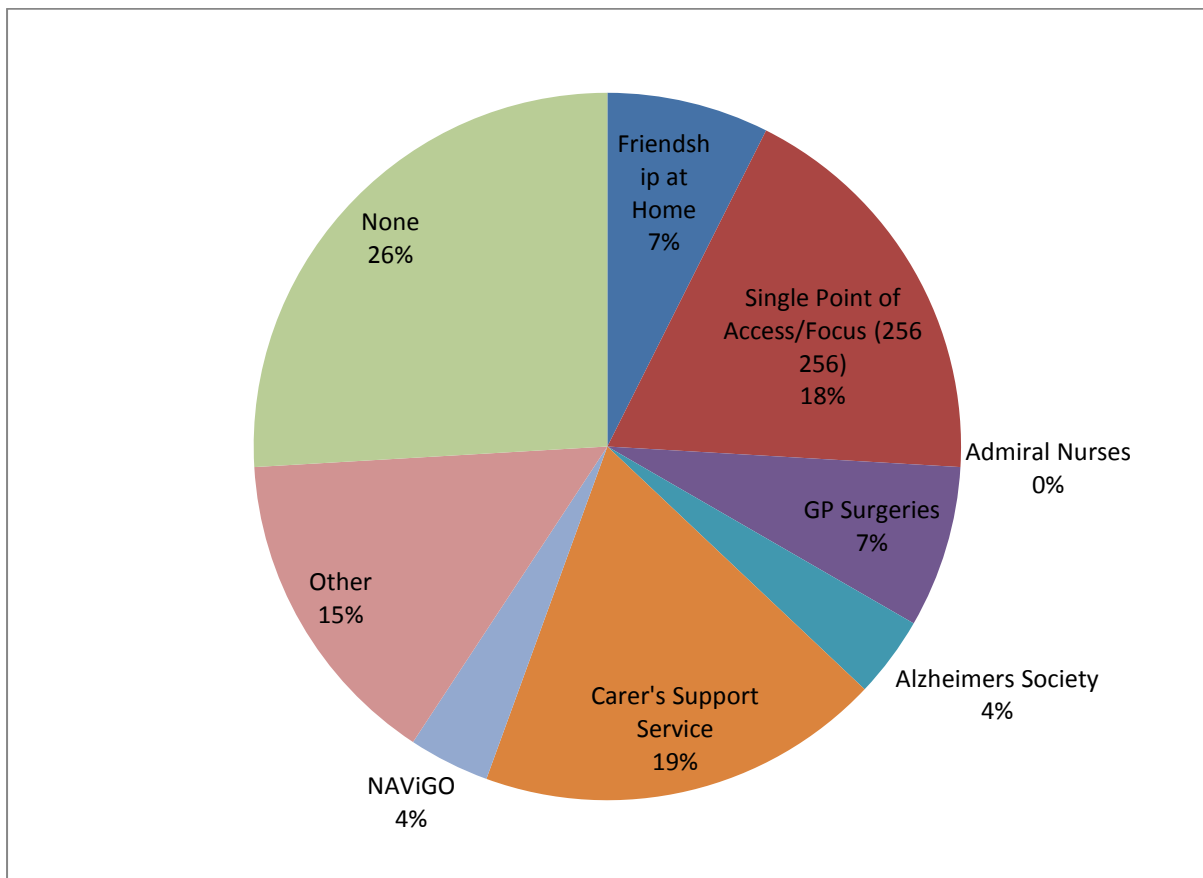
“I was encouraged to look after myself if I was going to be a carer and said I was very welcome to come and relax with the various chat/activity groups.”

Were you offered a confidential area to discuss your issue?



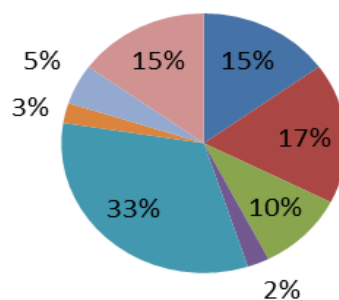
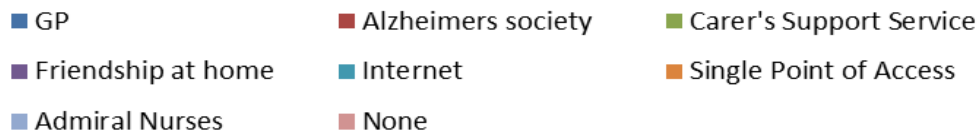
Were you signposted to any local support services?

Our volunteers were signposted to various local support services. Most of our volunteers were signposted to contact North East Lincolnshire's Single Point of Access (SPA) and The Carer's Support Service. Whilst others were signposted to Friendship at Home, Alzheimer's Society, NAViGO and their GP. Seven of our volunteers were not signposted to any service, and the remaining four volunteers were signposted to services such as Lincolnshire's Quality Care Services and the Carer's Monthly Newsletter, which is shown below under 'Other'.



When comparing the above results with those from the mystery shopper feedback gathered in pharmacies (below), it is evident that there is significantly more knowledge of social support services with professionals and staff within community venues than with those in pharmacies. Although there is a difference in sample sizes, it is reflected in the percentage of volunteers who were not provided with any information or signposted to a service.

Were you signposted to any of the following services?



Half of the community venues that were visited were Family Hubs (Sure Start Children’s Centres), which give help and advice on child and family health, parenting, money, training and employment. The core purpose of the Children’s Centres is to improve outcomes for young children and their families, with a focus on the most disadvantaged families, in order to reduce inequalities in child development and school readiness. The centres state that effective multi-agency working is widely recognised and plays an important role in their service.

Four of the centres researched the information for our volunteers upon request. However, the remaining six centre’s that our volunteers visited did not provide any information, advice or guidance. It is positive to note that the majority of our volunteers who visited the children’s centres reported that the staff were friendly and approachable, despite being given no information, advice or guidance. The most common recurring comment our volunteers received from Family Hubs was, “this service only deals with 0-19 year olds”. According to Barnardo’s (2013), the average age of a young carer is 12 years old. However this figure is based on young carers up to the age of 18 years old, and it is possible that not all categories of young carers have been taken into account. None the less, this average figure indicates that it is just as likely that a young carer may request information, advice or guidance from a Family Hub, and the feedback from our volunteers

suggest that they would not be able to appropriately signpost, or provide information, advice or guidance.

Key Observations

As part of North East Lincolnshire's vision and forward plan for dementia, the following action points were set:

- Encourage the Alzheimer's Society as the one main point of access after diagnosis
- We must improve sharing of information between agencies and organisations
- We should keep information current, up to date and relevant using a variety of formats- leaflets, posters websites, email and the media.
- By the 31st of March 2017, the Dementia Action Alliance (DAA) aimed to ensure that NEL becomes dementia friendly- i.e.: libraries, public facilities, hairdressers, shops, post offices, community centres and transport are dementia aware and supportive of those with dementia and their carer's as this will provide wellbeing and preventative benefits.
- The dementia strategy group and dementia action alliance were set to raise awareness of the support and services available to those with dementia and their carer's at different stages of the dementia journey.
- Dementia lead will ensure robust partnership working to promote each other's services and support and the sharing of information (ie: leaflets) across the full range of organisations and agencies

Conclusion

In conclusion, the information that is available in the community is inconsistent and in some cases unavailable. Within all community venues, including the pharmacies, staff do not consistently refer to main points of contact, carers support service or Alzheimer's Society. The Family Hubs work with families who have children up to 19 years old. However with an increase in people being diagnosed with early onset dementia this will mean that in the future family hubs may potentially be working with parents with dementia who have young families. Information needs to be clear and the signposting pathways which are already established need to be utilised more efficiently.

Further recommendations

In addition to the recommendations made previously in the “signposting support for Dementia Service users and Carers, HWNEL offer the following recommendations:

1. For all community venues to ensure staff are aware of and utilising the ‘Dementia Road Map’ included in the ‘Supporting your Journey to Living with Dementia in North East Lincolnshire’.
2. Ensure information on services is readily available for all staff.
3. Dementia Champions to be established within your community settings.