



Community Engagement & Intelligence

People's experiences of living with
Dementia in

Redcar & Cleveland

March 2018

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0800 989 0080

What is Healthwatch?

There is a local Healthwatch in every area of England. We are the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved and share their views with those with the power to make change happen. We also share them with Healthwatch England, the national body, to help improve the quality of services across the country. People can also speak to us to find information about health and social care services available locally.

Our sole purpose is to help make care better for people.

In summary - local Healthwatch is here to:

- Help people find out about local health and social care services.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.

As of 1 April 2017 Healthwatch Middlesbrough and Healthwatch Redcar & Cleveland are working together to deliver Healthwatch activities across South Tees.

Background on Dementia

Research carried out by the Alzheimer's Society suggest "there are currently 850,000 people with dementia in the UK, more than ever before, and this number is projected to increase"¹.

According to the Director of Public Health Annual Report 2017, "dementia is fast becoming the defining health issue of our time, with the numbers of people living with the condition projected to increase rapidly and no treatment to prevent, slow or cure the underlying diseases.

Statistics from 2015/16 indicated nearly 1,300 people with recorded dementia in Redcar & Cleveland, a rate significantly higher than England and similar to the North East average. The number of older people forecast to have dementia is expected to increase, driven by increasing numbers of older people rather than higher rates of disease"².

¹ Prince, M et al. (2014) Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society

² Healthy Minds Emotional Wellbeing and Mental Health in Redcar and Cleveland, Director of Public Health Annual Report 2017

In February 2015, the government published the “Prime Minister’s Challenge on Dementia 2020” which focused on boosting research, improving care and raising public awareness about the condition in England.

The Prime Minister set two key objectives for the Challenge on Dementia 2020:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- the best place in the world to undertake research into dementia and other neurodegenerative diseases.

To find out how Redcar & Cleveland were meeting the challenges set out by the Prime Minister’s Challenge we carried out engagement activities with people living with dementia and their carers to gather their views and experiences.

We had the opportunity to speak to individuals and their carers at the following venues:

- Carers Together Support Group, Guisborough
- Clevearc Day Centre
- Dementia training Session, provided by the University of Stirling
- Information & Dementia Session, Eston
- Westmorland Activity & Wellbeing Centre, Redcar

Community information and intelligence



During 2017 community services for older people were moved from Guisborough Hospital to Reed Marsh House, Coatham Road, Redcar. We have been told that the relocation of the clinic has caused some issues for Guisborough carers who have been used to visiting the Memory Clinic at Guisborough hospital. Carers also informed us that when they were visiting the clinic, the signage was unclear leading to confusion for both the patient and carer.

- One carer informed us that she was unable to travel to Redcar with her husband as he was confused about where he was going and became very upset, resulting in the visit being cancelled.
- “Memory clinic is not very good. It’s not well signed and there is a parking eye in the car park. You are only allowed to stay for 45 minutes maximum”.


- The clinic is badly signed. Carers are having problems finding the memory clinic and are unsure where it is in Redcar. There are only small A4 posters on the windows of the clinic, not making it clear. Carers are going to the Community Heart instead, it's very confusing for people with dementia.
- Parking at the side of the clinic is confusing as the car park is shared with Coatham GP surgery. It needs highlighting that they can park there. Also, there is a parking eye with a maximum stay of 45 minutes. You must remember to put your car registration in the monitor in the clinic.
- "Why go to the memory clinic - not a lot out of the visit."
- "The clinic does not speak to the person with dementia and communicate through relatives which is very frustrating. Relatives have to lead any questions.
- "We had to wait a long time for my father's prescription. It should have gone straight to the pharmacy. In the end we had to wait 10 days despite several phone calls."
- "We requested that the clinic do not send appointments direct in the post to my father, as he hides them but they still do it. A home visit was arranged but we found the letter too late for us to be there and had to cancel it. If it had gone ahead it would have been very confusing and stressful if someone had turned up without a family member being present."

We spoke to the Team Manager at Reed Marsh House in Redcar to gain a better understanding of the services provided by the clinic and to share some of the feedback we had received. We were informed that the clinic had moved from Guisborough to Redcar following a mapping exercise that identified that the highest proportion of patients came from the TS10 area, however appointments can still be carried out at the patient's own home if this is more convenient.

The Team Manager was aware of the issues regarding signage of the clinic and informed us that they hoped that this will be resolved soon.

We asked the Team Manager what information they provide to patients at the point of diagnosis. They informed us that they gave information regarding the type of dementia they have been diagnosed with, a Post Diagnosis Information booklet, The Dementia Guide and information on services provided by Carers Together. We asked if there was anything else they felt would benefit patients and their carers, they informed us that patients frequently asked about other

support groups and activities in the area. We were advised that this was currently being compiled and that that we could review it prior to distribution, to see if it was meeting the needs of the people who need it and provide feedback.



Information, support and training

This was one of the main issues for those living with dementia and their carers. We spoke to people at varying stages of their dementia journey so their experiences of receiving information were quite different. Most people felt that it would be useful to be given information and or training as early as possible following diagnosis. Even though all the information may not be relevant at the time, they would feel better equipped to manage when circumstances change.

- “I have not been given any information or support. I feel that I always have to fight for information. I have never been offered dementia training, I would have liked to receive it to understand more about my father’s behaviour, etc.”
- “I am unsure where to go for help and advice.”
- “Information should be given at the right time. I didn’t receive support or help till two and a half years after diagnosis.”
- “No information is given about the dementia journey, memory clinic, groups, dementia hubs or how to become a dementia friend, which may have given me a better understanding of the disease.
- A lady who cares for her husband who has dementia, informed us she was unsure where to go for help and needed some advice with regards to carers allowance and what she was entitled too. This made her very upset and she became ill herself "chasing" information and trying to find help. She feels that had she been given this information at early diagnosis of her husband’s condition it would have been a great help and relief.
- One carer told us that they feel that the dementia pathway for professionals can be unrealistic. “It seems that everyone is treated the same when in fact there are several types of dementia and it can affect people in different ways they should be treated as an individual. Also, the majority of the carers are not coping very well, they are basically told to get on with it. This is becoming very upsetting and stressful for the carers.”
- “We need to ensure that people living with dementia and their carers feel supported to manage their condition to enhance the quality of their lives.”

We spoke to the Carers Information and Support Service Manager from Carers Together, who gave an overview of the Dementia Advisory Service. We were told that they have established good links with the Memory Clinic, and that patients and their carers/family are signposted to them. This is the only dedicated support available.

They have also organised dementia training for carers, provided by Stirling University, which we attended. The carers we spoke to on the day thought the training to be excellent, and many expressed that they wished they had received it earlier as they felt it would have helped them cope better. It is unclear how many more of these sessions will be provided within Redcar & Cleveland and only a small proportion of carers will be able to attend.



Another key issue raised by those living with dementia and their carers was a lack of social activities and groups to attend in their local community. They felt it important that they have an opportunity to meet others and share experiences.

- “It would be good if there was a café where we could go and have a chat and talk to others”
- “Sometimes I feel very isolated and stuck at home as there is no-where to go”
- A lady told us she attended a “sing-a-long” session with her husband, organised by the Dementia Advisory Service. However, she felt it was not suitable for her husband as the others attending were more advanced with dementia. This had made her upset and put her off attending in the future.
- “We need more support and places to go for people living with dementia in Guisborough, rather than going to Redcar. The bus only runs once an hour and it can be difficult getting there.”

The Dementia Advisory Service provides activity groups, mainly in Redcar and a Dementia Carers Support Group in Middlesbrough. We received excellent feedback about the groups that are established but were advised that there was a gap in service for those who are in the early stages of dementia. The people we spoke to

were unsure of any activity groups outside central Redcar and felt this could lead to further isolation.



Although people told us it was important that they had access to social activities and groups that were catered to them, it was also important that they could carry on living their lives in their community, doing things they normally do, while feeling safe and supported. They felt that this was one of the key factors in living well with dementia.

- “I wish Redcar & Cleveland were more dementia friendly like Middlesbrough, they even have dementia friendly screenings at the cinema”
- “It can be very stressful doing simple things like shopping or visiting a café. If more places were dementia friendly this would be really helpful”
- “There does not seem to be a lot of awareness of dementia where I live, and the lack of understanding has created a certain amount of stigma about the disease.”
- “I do not tend to go out much with my wife as her behaviour can be unpredictable. Places that are dementia friendly can ease the pressure of going out as you feel you have support and understanding.”

Throughout our engagement activities, it is apparent that a dementia friendly community can help address many of the issues that those living with dementia and their carers face. If businesses, organisations, shops and leisure facilities were dementia friendly, it would allow for a host of activities and opportunities for those living with dementia.

There is a great deal of enthusiasm within our area to work towards becoming a dementia friendly community. Staff and volunteers from Healthwatch have recently become Dementia Friends, and two members of staff have become Dementia Champions. We have promoted Dementia Friends training in our GP surgeries and in other health and social care settings and will be working in collaboration with other organisations to support Redcar & Cleveland becoming dementia friendly.

You can find out how to become a Dementia Friend or Champion by contacting the Alzheimer's Society or by visiting their website.

<https://www.dementiafriends.org.uk/>

Summary of intelligence

- Patients are experiencing difficulties in accessing the Memory Clinic due to poor signage and we have been informed that this will be rectified in the near future.
- Patients are unsure of the role of the Memory Clinic and would benefit from a clear communication of the services provided and what can be offered in their ongoing care. For example, explanation of changes in behaviour and crisis contact details.
- Information provided to those living with dementia and their carers appears to be a key issue, whether that being about their condition, other services that can support them or what is on offer within the community. Having the right information at the right time seems to be important as well as ensuring that there is consistency on how this is distributed.
- Redcar & Cleveland is not currently a dementia friendly community and those living with dementia and their carers feel that they would be able to have more fulfilling lives if steps were made to rectify this. A dementia friendly community would open up more opportunities without relying on bespoke activities for those with dementia.

Acknowledgements

We would like to thank all of those who shared their experiences and views and the organisations who gave us the opportunity to carry out this engagement.

We will share this intelligence with relevant stakeholders to ensure that the views of the people we spoke to are included in the decision making to improve people's experience and access to services.



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