

# healthwatch County Durham

## Dementia Support

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Research into the experience of patients in County Durham

(January 2019)



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## Healthwatch County Durham

Healthwatch County Durham is the county's consumer champion for health and social care, representing the voices of current and future users to decision makers.



### **We listen**

We listen to patients of health services and users of social care services, along with their family members or carers, to find out what they think of the services they receive.



### **We advise**

We advise people how to get the best health and social care for themselves and their family. We provide help and information about all aspects of health and social care provided in County Durham.



### **We speak up**

We make sure that consumers views are heard by those who provide health and social care. Wherever possible we try to work in partnership with providers to influence how they make improvements.

## Executive summary

In 2017 Healthwatch asked the public in County Durham what their priorities were for us to look at in 2018/19. There were six proposals to prioritise based on intelligence gathered from our signposting work and information provide by partner organisations. Investigating Access to Dementia Support Services was selected by the public as one of their top four priorities.

We wanted to find out more about referrals to Dementia Support Services. This included:

- Were referrals being made?
- Were they timely?
- Were there any significant variations across the county?
- Could we identify any good practice?

We carried out a series of different engagement methods to gather views and experience of patients and staff:

- Creating a survey which was used on line
- Talking to people with dementia
- Talking to carers of people with dementia
- Talking to organisations who support patients

We received 50 responses to our surveys, 16 were received from an on-line survey and 34 from a range of engagement activities.

## Observations and Recommendations

We had hoped to be able to feedback good practice by identifying any differences across the county in the referral processes, however at the conclusion of the project there were no clear variations in patient experience identified, despite a considerable amount of work being undertaken with stakeholders. We will continue to analyse any intelligence we receive about dementia support and services. If we become aware of any particular good practice over the next 6 months we will investigate and report back to our board and relevant partners by updating this report.

The majority of the people who completed the survey were happy with the way in which they had been referred into services.

Throughout our visits to organisations, support groups and venues for dementia patients we encountered a wide range of services available both for patients and carers. There were lots of good examples of support which enabled patients to remain involved in their communities.

Some of the key messages from patients generally were:

- Early diagnosis was important, for a significant number of patients it took over 4 weeks for a referral to other services
- Timely referral to, and advice about support networks helped patients, carers and families through difficult and challenging times

In our conversations we were told some of the things that were important to one particular family in their experiences of living with a partner who developed dementia:

- GPs should refer patients to support services at a very early stage in diagnosis which would mean they can have prompt help, support and advice from trained individuals
- Speedy diagnosis, this patient waited 3-4 months for a brain scan which was difficult for everyone involved
- Having access to good quality information, if it had not been for family, friends and a neighbour, this carer would not have known how to access help and support

## Background to this work



In 2017 Healthwatch asked the public in County Durham what their priorities were for us to look at in 2018. There were six proposals to prioritise based on intelligence gathered from our signposting work and information provide by partner organisations.

Investigating Access to Dementia Support Services was selected by the public as one of their top four priorities.

The Mental Health and Wellbeing Strategic Plan 2018-21 identified the following priorities/objectives for dementia services:

- Improving public and professional awareness and understanding of dementia
- Ensuring early diagnosis and intervention for people with dementia and their carers
- Providing good quality information for those with diagnosed dementia and their carers
- Ensuring people with dementia can live well at home throughout their dementia journey

Healthwatch wanted to support the priorities identified in the strategy by finding out more about referrals to Dementia Support Services. This included:

- Were referrals being made?
- Were they timely?
- Were there any significant variations across the county?
- Could we identify and share any good practice

## What we did and what we found

We carried out a series of different engagement methods to gather views and experience of patients and staff:

- Creating a survey which was used on line
- Talking to people with dementia
- Talking to carers of people with dementia
- Talking to some of the support services, with an aim to try to identify any particular GP practices where there had a good record of timely referrals, to see if we could capture any good practice



We received 50 responses to our surveys, 16 were received from an on-line survey and 34 from a range of engagement activities. From our survey, we found that:

- 46 (92%) of the 50 people with dementia had their problems with memory identified by themselves or a family member
- 44 people (90%) went to see their GP once they had concerns and of those people 33 (76%) felt supported by their GP
- Nearly all the patients told us their GP had referred them to other services
- 18 patients (45%) said this took longer than 4 weeks
- 35 (80%) of patients were happy with the support they received

“The lady came, she was very helpful in all ways and we saw a specialist very quickly who diagnosed him straightaway. We attend a memory clinic every year now instead of twice yearly.”

## Case Study

In September we spoke to Dave\* about his family's experience. This is their dementia journey:

*Dave is the full-time carer for his partner who is living with dementia.*

*She was 64 when she was diagnosed and Dave arranged power of attorney straight away.*

*His father had vascular dementia therefore he recognised the early signs.*

*He bought his partner an automatic car to see if that would help with her co-ordination with the pedals. He also changed the microwave from a digital one to a turn dial as she was burning food. Dave was making her a sandwich for lunch before he went to work, she was putting it in the bin and walking around to the local shop to buy ice lollies instead.*

*The GP did a memory test and she could not tell the time.*

*She was referred for a brain scan which took 3-4 months for the appointment from going to the GP.*

*She now has someone that comes out every 2 weeks to see her.*

*As she has lost the use of her legs, an Occupational Therapist has helped the family access aids to help around the house.*

Dave feels that getting pointed in the right direction from diagnosis is crucial with advice about benefits and support:

- Dave was advised by a neighbour that Age UK County Durham could help him with benefit and PIP forms.
- He has also registered with Durham County Carers Support.
- His partner is now incontinent and was told by a neighbour that she would be entitled to free continence pads which he did not know about.

If it was not for family and friends, he would not have known about the support and care that was available when he needed it.

\* Name changed



## Services available

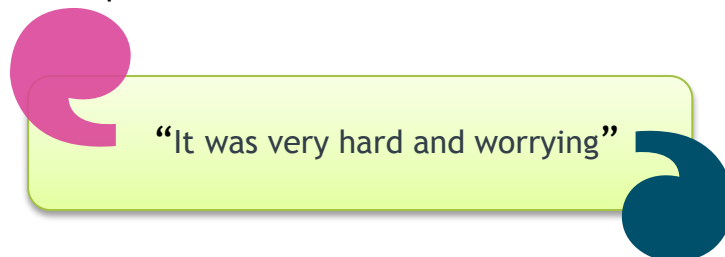
Over the engagement period we visited a number of excellent support groups around the county. These varied from memory cafes, singing for the brain and games for the brain. All the groups run by staff from the Alzheimer's Society are also supported by volunteers.

Overall the groups are well attended and a great way for family members and carers to meet new people and receive support from members of staff.

There is no pressure to attend every session, we found that family members who had lost loved ones through dementia still came to the groups. They found comfort in listening to other people in the same situation.

## Conclusions

In conclusion we found the majority of patients and carers were happy with the support and services they accessed, although not everyone felt supported by their GP and sometimes the referrals to other services took a long time, with some patients telling us they had to find support services themselves rather than being signposted by a health professional.



Although anecdotally we had been told there were variations across the county in the standard of referrals and the timeliness of the support patients and families received, we were unable to evidence this in the work we undertook. The stakeholders we engaged with were unable to provide any factual information; therefore we feel that we are not in a position to make any particular recommendations for referrals into services. However we can say that the speed of diagnosis and the ability to access support quickly makes a great difference to patients and families.

We will continue to analyse any data received over the next 6 months and if anything meaningful is discovered we will update our report and share this with relevant organisations.

## Response from Neil Jarvis - Chair of the Dementia Strategy Implementation Group:

“Good to see that there was some consistency across the County in terms of the services available and that the majority of people were happy with the support received.

Very pleased to get positive feedback on the services available. We have done a lot of work in recent years on dementia services including the Dementia Advisor service with Alzheimers Society and dementia friendly communities etc. We have made dementia one of our priorities so having good feedback on that is great for us.

For actions, clearly the main issue to come out of this for future work is the need for speedy referral into support services and the role of the NHS in that process - either GP’s or clinics etc. To see some focus on areas of improvement there is not a surprise and, though we have done quite a lot of work on that already, we definitely need to make sure we keep the focus on it in future as a priority.

As we move to integrated commissioning with the NHS over the next year that process can only help with knitting services together and making sure the whole system works for people, so I’m optimistic we will make further progress.”

We would like to thank everyone who completed our survey, the GP practices who shared their processes, and the patients and carers who took the time to talk to us about their experiences.

**Thank You**

As part of the project we spoke to the following groups:

Alzheimer's Society - Chester le Street

Beamish Museum - Orchard Cottage

Dementia Café - Chester le Street

Durham County Carers Support

Games for the Brain - Barnard Castle

Hospital of God

Memory Café group - Consett

Memory Lane Café - Seaham

North East Ambulance Service

Pioneering Care Partnership

Singing for the Brain - Barnard Castle

Singing for the Brain - Chester le Street

St Cuthbert's Hospice

## Appendices

1. Survey about the referral system
2. A list of the first symptoms patients / family were aware of (copied from survey)
3. A list of comments about patient experiences (from survey)

### Appendix 1: Survey

As part of our workplan for 2018/19 Healthwatch County Durham are looking at the referral system made by GP practices for people living with dementia. It appears that there is a number of different ways referrals are made by GPs and Healthwatch would like to find out about any concerns and share good feedback.

1. Are you completing this survey as:
  - A person living with dementia
  - A family member/carer of a person living with dementia
2. Who first noticed signs of problems with memory or other symptoms?
  - Yourself
  - Family member/carer
  - GP during appointment for another condition
  - Other professional
3. What were the signs?

4. If it wasn't the GP that noticed the first signs of dementia, did you/family member/carer go to the GP?
  - Yes
  - No

5. If yes, did you/family member/carer feel supported by your GP?

- Yes
- No

6. Did your GP refer you to access any other services?

- Yes
- No

7. If yes, was it within

- 1-2 weeks
- 3-4 weeks
- 4+ weeks

8. What service did your GP refer you to?

9. Were you happy with the support you received from your GP?

- Yes
- No

10. Any other comments about your experiences

11. Please provide the first part of your postcode: \_\_\_\_\_

12. Please select your age group

- 18 – 24
- 25 – 49
- 50 – 64
- 65 – 79
- 80 +

13. Are you?

- Male
- Female
- Other

## Appendix 2: List of early patient symptoms

Repeating themselves. Forgetting what they were doing. Forgetting how to work things.

Forgetting pin number at the bank.

Repeating himself asking the same question quite quickly

He didn't want to walk, very irritable. Always had a good appetite.

Asked about dementia check and was referred

Mother had dementia so knew the signs - forgetfulness

Went to GP due to loss of mother Had anxiety and stress but did not get any better.

Forgetfulness

Memory loss

All mixed up, giving people wrong names

Couldn't remember a card game that he used to play years ago

Hallucinations & delusions.

Memory loss

Forgetting. Falling over.

Being unable to attempt skills that he had used all of his life , confusion , lack of interaction

Memory loss and repeating herself. Accusing people of being in her house when she wasn't in. Confusion.

Initial signs of forgetfulness and repeating conversations.

Bad driving. Confusion. Irritability. Forgetfulness.

Forgetfulness, repetitive speech

Less interaction with others

Repetition and forgetfulness

Loss of things you told him. Could not remember

Loss of memory where things have been placed, dates, time. What they have just done.

Lapse of memory

Forgetfulness unable to comprehend conversation day, time etc.

forgetfulness and short term memory loss

Personality changes, short term memory loss

Forgetfulness doing strange things and repeating himself  
Paranoia and memory loss  
None collection of tablets and repeating questions over.  
Forgetting  
Unfinished sentences  
Forgetfulness  
Can't remember  
Being forgetful and asking the same thing over and over again  
Forgetting simple topics  
Forgetting to do things, cooking meals and doing them again.  
Repeating himself, forgetfulness  
Memory Loss Confusion  
Forgetting things and asking me the same question, plus he had a Grandmother who had it.  
Did not know where to put plates in the cupboard  
Forgetting things  
Forgetting things, Mood swings, doing things out of character.  
Burning tea. Not being able to use microwave. Too many things happening.  
Forgetting what objects were, people were and what was just said  
Forgetting things that had happened, names. Difficulty with sudoku  
Poor memory - forgetting things  
Forgetfulness - problems with numbers. Problems driving, times, dates  
Forgetful. Repeating conversation  
Memory loss/process problems (eg cooking, tv selection, etc)

## Appendix 3: Comments about patient experience

GP advised applying for power of attorney before it would become difficult

Why was my Mother given an ECG when she went to the Practice Nurse for her memory test?

On medication keeps him on a level pace. Also mum is showing signs of dementia and is very confused. Been to see the GP but she passed memory test and will not go back and see GP again at the moment

Once district nurse and GP came when he was in the area

Very good support from GP

Support from family

Will not go into the garden on her own

Very much happy. Referred to Bowes Lyon unit. Frightened by patients at West Park, Bishop Auckland was better. 3 years been diagnosed with vascular dementia and Alzheimer's. Wife got violent in February and was sectioned now in a care home.

Happy with support

Always felt that there was something not right. Was going to dance classes and got transport back and forth but that has finished now. Now is having a 7 week course for physio. Been diagnosed for 3 years but sometimes he can be very aggressive and won't be wrong at all.

Happy with the GP

Lack of support for carers in the community. Services in rural areas very difficult to access.

It's a bloody hard journey

My mother gets quite upset when the word dementia or Alzheimer's is mentioned in relation to her. I think a meeting with a family member/carer should be carried out before using these sort of words when speaking to the patient to discuss how their condition should be discussed in their presence. I felt that I had to pull social workers to one side to warn them not to use certain words. My mother's memory although short does not prevent her understanding the implications of dementia/Alzheimer's and is very frightening to her.

We got as far as asking Mam if she wanted a diagnosis and she refused. Where do we go from here?

After 2nd apt I was told husband didn't have dementia. Appt with Dr 3 months later and was told he did but I never received a letter with diagnosis

The lady came she was very helpful in all ways and we saw a specialist very quickly who diagnosed him straightaway. We attend a memory clinic every year now instead of twice yearly.

All very supportive Extra support items in house ie rails inside and out door contact, bath seat/board



Asking questions patient did not think he had dementia. Social worker calls to see him at the care home. Information was given via Auckland Park.

Only had one visit from a CPN since diagnosed no other contact with anyone because no medication can be given.

We hear about the importance of early diagnosis of dementia yet an early diagnosis is almost impossible. CPNs are using diagnostic tools that are not fit for purpose and do not take enough notice of family/carers.

After getting to the point of referral from GP to Auckland Park I have had some support but also found out a lot myself through the internet.

After 3 years discharged from Derwent Clinic lonely time as a carer.

Not very helpful

After being referred to hospital (---) was seen a couple of times and then discharged having vascular dementia and saying they could do no more for him

When we first went to the consultant he shut down and wouldn't speak to her. He was in denial and when dementia was mentioned he became aggressive.

Consultant treated him for depression had to go back to GP. GP support was good would not have got help without him pushing

Getting point in the right direction from the start with advice about benefits. Did not even know about a District Nurse.

From memory I think the services we accessed were found by ourselves, not signposted by the GP. Particularly Alzheimer's society, St Cuthbert's Hospice.

NHS professionals confused dementia with MS symptoms.