



Healthwatch Hartlepool Investigation
into Patient Experience of Dementia
Diagnosis

Update Report

September 2016

MISSION STATEMENT

“Healthwatch Hartlepool has been established in a way that is inclusive and enables involvement from all areas of the local community. We wish to involve those who are seldom heard.”

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1. Background

1.1 Over recent years at both national and regional levels, there have been few issues and conditions that have attracted as much interest and coverage as dementia. It is estimated that around 850,000 people in the UK are living with dementia and that a further 700,000 are providing care and support to people with the condition.

1.2 Dementia is an umbrella term for a range of conditions which impact upon the functioning of the brain. The most common types are Alzheimer's disease and vascular dementia; less common forms include Lewy bodies and frontotemporal dementia.

1.3 Dementia is not a normal part of aging and will affect people differently. Symptoms can include problems with memory, thinking, concentration and language. One may become confused, have changes in mood, behaviour and emotion.

1.4 Recognition has also been given to the importance of achieving timely assessment for possible dementia. Diagnosing dementia, and the type of dementia someone has is important. It will ensure that people with dementia get the right support and treatment quickly and can plan for the future.

1.5 In most cases the person's G.P is the first person to be contacted and if dementia is suspected a referral will be made to a memory clinic or specialist. G.P's will also routinely ask certain patients who are at high risk of developing dementia whether they are concerned about their memory. This includes patients with Parkinson's disease, those who are over 60 and have diabetes or a heart condition and those with a learning disability.

1.6 However, making a diagnosis of dementia can be difficult, particularly at the early stages as there is no one simple test for the condition and symptoms can be very similar to many other common conditions.

1.7 There is also considerable evidence that despite the headway that has been in developing “dementia friendly” communities, there is still considerable fear of a diagnosis of dementia. This can have a profound effect on the willingness of individuals to acknowledge that there may be a problem and to seek help from their G.P.

1.8 As with many other conditions, early diagnosis of dementia can have a positive impact on how the progress of condition is managed and on the quality of life of the patient, their family and carers.

1.9 Recent government figures suggest that at both local and national levels there have been significant improvements in diagnosing dementia and in developing subsequent care pathways. This report looks at dementia diagnosis in Hartlepool from the perspective of both G.P practices and patients, their families and carers. A copy the NICE Dementia Pathway guidance is shown in Appendix 2.

2. Methodology

2.1 Healthwatch Hartlepool decided to look at the issue of dementia diagnosis as part of its ongoing interest in the provision of dementia care and treatment services.

2.2 Also, despite indications that diagnosis rates in the Hartlepool and Stockton Clinical Commissioning Group (HAST CCG) area were improving, concerns were identified that some patients were reluctant to acknowledge that they were experiencing memory problems due to stigma (perceived or otherwise) associated with the condition.

2.3 In November 2015 questionnaires were sent to all G.P surgeries in Hartlepool. The questionnaire asked about the process the individual practices followed with patients from a possible problem being identified through to diagnosis and ongoing treatment and support.

2.4 In total, eight practices returned the questionnaire, a copy of which, together with a summary of the responses received can be found at Appendix 1.

2.5 At the same time we also visited Caroline Ryder-Jones from TEWV who described the work which is undertaken through the Memory Clinic with patients who have been referred to them from G.P's and by other means.

2.6 Finally, a series of discussions took place with individuals and groups of patients and carers who have recent experience of dementia diagnosis. In total, we spoke to more than 30 patients and carers but encountered some difficulties finding people who were willing to talk openly about their experiences.

3. Findings

3.1 G.P Feedback

(i) Generally, we received a positive impression of the dementia diagnostic services provided by the eight practices who returned questionnaires. It must be said however, that overall, practices were slow to respond and despite several reminders only 50% of the practices in the town returned the questionnaire.

(ii) There was a clear indication that all surgeries undertake preliminary examinations and screening of patients if dementia is suspected. This includes blood and urine tests as well as basic memory tests (such as the 6 CIT test). Some Practices said that patient history and general mental health were also considered.

(iii) Several practices said that they had detailed discussions with patients/carers /family members at this stage and consent was gained to investigate further.

(iv) All practices indicated that a referral to the Memory Clinic would be made once initial tests had been concluded and results indicated that further investigation was needed.

(v) On receiving confirmation of a dementia diagnosis from the Memory Clinic, most practices indicated that the patient was added to their Dementia Register and would subsequently be called to an annual dementia review meeting. Most practices also said that they would be involved with other agencies in planning subsequent nursing and social care inputs.

(vi) Most practices said that dementia diagnosis had shown a slight increase in the previous two years. They also commented that patients were generally more aware of the condition and its symptoms and therefore more prepared to request screening at an earlier stage. Some also commented that greater awareness was also leading to relatives and carers being more likely to raise concerns.

(vii) In general, practices are promoting awareness and the importance of early diagnosis through surgery based information and discussions during consultations. It was also reported that national publicity is also helping to raise awareness levels.

(viii) Some practices said that patients were waiting slightly longer to access Memory Clinic appointments but overall, waiting times were not seen as excessive and all practices were of the opinion that diagnostic and treatment services have improved.

(ix) All practices that responded have provided staff training around dementia and in most cases this has included administrative and reception staff. Some reported using e-learning packages and others said that staff received annual dementia updates and that the issue was regularly discussed at team meetings.

(x) Some practices reported offering newly diagnosed patients care planning meetings which recognise the individual nature of each patient's dementia and seek to develop care packages which are right for that person. Patients are also encouraged to bring a relative or carer to review meetings whenever possible.

(xi) Most practices also reported that they have made attempts to make surgeries dementia friendly with examples being the use of easy read signage and introducing longer appointments.

(xii) Practices also reported that systems were in place to flag up patients who were at particularly high risk of dementia. In some practices patients with Learning Disabilities were offered dementia screening as part of their annual health check although some difficulties were reported in administering the 6 CIT test.

3.2 Patient/Carer/Family Feedback

(i) Around 30 patients, carers and family members with recent experience of the dementia diagnosis process have input into our investigation. This has been through one to one discussions and larger focus group events. We are extremely grateful to all those who have taken time to speak to us and their input is are extremely valuable.

(ii) Gathering information has proved to be quite difficult and on occasions people have been reluctant to talk about their experiences. We feel that this indicates that despite the enormous amount of excellent work that has happened over recent years aimed at raising awareness and understanding of dementia, it is still a condition which some patients are reluctant to talk about.

(iii) It is often said that each person with dementia will have their own individual experience of the condition. Our investigation indicates that this can also be said about the experiences individual patients have during the diagnostic process. The feedback we received from G.P's shows that broadly similar diagnostic processes are being followed and that pathways which leads to a referral to the Memory Clinic are fairly consistent. However, the point at which diagnosis occurs and the emotional, psychological and personal impacts on individuals vary greatly.

(iv) Some patients reported that they thought they had dementia before they spoke to their G.P –

“I know the signs and knew I had it even before I went to see my doctor”

For others it came as a complete surprise and in some cases was picked up as a result of other medical inputs.

“I went for an eye test and the optician said I should see my G.P”

(v) Some patients reported that a significant issue or event had caused them to consult their G.P -

"I was driving home from work after a training day. I got to a roundabout and could not remember what to do"

Others said that friends or relatives had noticed changes before they had themselves, and on occasions, a significant period of time could pass before they raised concerns with their G.P.

(vi) In all cases, both patients and family members reported that this was a particularly stressful time for all concerned and in most instances the referral to the Memory Clinic was triggered by the G.P although one patient said that their referral had happened via the hospital and two others said that they were referred following a stay in Sandwell Park.

(vii) Both patients and family members reported that generally once a referral to the Memory Clinic happened, the appointment came through quickly.

(viii) The diagnosis process is extremely stressful for patients and their families and carers. Concerns were raised by some patients about information and communication during the diagnosis process and in some instances poor communication had increased stress and anxiety –

"I felt that the way I was given my diagnosis was insensitive.....I felt like there was no hope at all"

"I still don't know what type of dementia I have and what can be done"

"It was one of the most stressful times of my life"

However, some patients reported that communication had been good and they were kept well informed at all stages.

"My G.P was good, I was referred quickly and he kept me well informed".

(ix) Some patients reported that their individual diagnosis had taken several months to complete. This was most common among those patients who had experienced the onset of dementia in their 50's or early 60's. It was reported that in such cases G.P's had initially looked

to rule out other conditions before dementia was considered. In one instance a patient reported that their initial diagnosis had been for depression and that they had gone through a very traumatic period before their dementia was properly diagnosed.

“It took an age to get my diagnosisand I am still not sure what it all means”

(x) Patients and family members often reported that they had been given information verbally and in written form but had found it too much to take in and retain at the time and consequently were now unclear about their diagnosis and how the condition was likely to develop.

(xi) The impact on carers and family members can be immense both during diagnosis and subsequently. During the course of our investigation we heard many powerful accounts of the life changing impact the condition has on individuals, carers and family members.

(xii) Several patients and family members reported that their decision to see their G.P had been made following a visit to The Bridge where they were given information and advice about dementia and the importance of early diagnosis. Feedback regarding the Bridge and the work it does in supporting individuals with dementia and their families and carers, was extremely positive.

(xiii) Some patients commented that they had received very little post-diagnosis support from their G.P. Most surgeries who returned questionnaires indicated that patients with dementia will have an annual health check during which their condition is reviewed. They also reported that patients could also see their G.P at any time by appointment if needed.

4. Conclusions

4.1 Overall there was evidence that diagnosis and associated procedures have improved across the G.P practices that returned questionnaires. Awareness levels amongst all staff appear to have improved and staff training on dementia awareness now happens routinely in most Practices. This includes administrative and reception

staff as well as well as G.P's and nurses. However, service development in this area is still a "work in progress" and there is still scope for further improvement.

4.2 Diagnosis of dementia for an individual, their family and carers is still an extremely difficult and traumatic process. There was evidence that some patients and their families feel that there is still a stigma attached to the condition and this can impair their willingness to seek help and support at an early stage.

4.3 Much has been done to address some of the misconceptions and prejudice around the condition, but more is needed if the ambition of creating truly "dementia friendly communities" is to become a day to day reality.

4.4 Concerns were raised by some patients about the level of ongoing support they received once diagnosed. This suggests that improvements could be made to this aspect of ongoing care and consideration given as to how understanding can be checked at diagnosis.

4.5 Evidence was presented by those with dementia and family members and carers which showed that communication processes at all stages of diagnosis can be problematic. We acknowledge and accept that due to the nature of the condition and the stressful nature of diagnosis, communication can be difficult. However, it is not acceptable for patients to be unclear about any aspect of their diagnosis and its implications for the future. Every effort should be made to ensure that all parties are kept fully informed, and as far as is practicably possible have understood all aspects of diagnosis and ongoing implications.

4.6 Patients who had experienced the onset of dementia at an early age more frequently reported problems and delays in reaching a diagnosis of their condition, and in one instance the patient had been incorrectly treated for depression for a period of time. In some instances these patients also found it hard to accept and come to terms with the diagnosis as the condition was seen as "something that only happens to old people". We accept that our sample group is

relatively small but it does seem to indicate that some further work is needed in order to develop the support received by this age group during diagnosis and beyond.

4.7 Communication between G.P's and the Memory Clinic in most instances appear to be working reasonably well and as stated earlier the introduction of The Bridge Centre has been extremely helpful in providing additional information and support to patients and family members.

5. Recommendations

5.1 That the findings and conclusions above are noted and acted upon by all relevant parties and that Healthwatch Hartlepool continues to monitor the ongoing development of patient experience of service delivery in this area.

6. Acknowledgements

Healthwatch Hartlepool would like to thank all organisations and individuals who have provided our members with information and hospitality during the course of this investigation; their help has been invaluable.

Healthwatch Hartlepool Dementia Diagnosis and Pathways Questionnaire

1) When a patient comes for a consultation, and describes/displays symptoms which suggests dementia as a possible/probable prognosis how would you proceed?
*A template such as a G.P log is used to assess and depending on the results of this patient will be offered blood tests for dementia screening including calcium, vitamin B12 and folates. A referral to memory services would also be initiated depending on results.
*Look at patient history, duration of issues and mental state. If further examination needed, bloods and ECG.
*Do basic assessment as per Tees Dementia Screening.
Ask if patient has any concerns with memory. If yes ask patients consent to assess. Undertake GPCOG if consent given. Depending on score, bloods and urine taken and refer to Memory Clinic. Also discuss with family/carer.
*Discuss if the patient would like to proceed further. Gain consent to screen/investigate. Establish if the patient has capacity to make decision.
*GP takes a detailed patient history, particularly around symptoms associated with dementia. Clinician does CIT scoring test, if return score over 8 patient is referred to Memory Clinic.
*Check bloods/MMT screening and refer to Memory Clinic (2)
2) At what stage would a patient be referred to the Memory Clinic in order to access, diagnosis and support?
*As soon as concern is expressed or identified.
*If there is demonstrable cognitive impairment on MMT
*If score 8 or more on test will be referred.
*If the screening test showed referral appropriate and all tests have been completed.
*Once tests have been completed an assessment is done
*Following investigation and mental state examination a referral is made to Memory Clinic.
*If symptoms and or results of blood tests and GP log show

possibility of diagnosis patient is referred.
3) What ongoing involvement do you have with the patient regarding their condition once they have accessed the Memory service regarding their memory condition?
*Annual review as a minimum standard or earlier if needed. Blood test also done annually or sooner if needed.
*Depends on risk factors and patients circumstances, eg living independently, in a care home etc.
*Annual review, medication request.(2)
*Would deal with any medical problems as we normally do and await feedback from Memory Clinic. Arrange any nursing or social service interventions as appropriate.
*Provision of medication under shared care guidance. All patients with dementia diagnosis has it placed on their medical record. Other primary care services as normal.
*If a patient is diagnosed they will be added to our practice dementia register. They will be invited for yearly dementia reviews and the relevant GP will create a dementia care plan. As always patients have open access to GP's.
*Followed up in routine clinics after we receive results from the Memory Clinic. Added to practice dementia register.
4a) Over the last two years has the level of dementia diagnosis at your practice changed, if so please quantify?
*Increased due to improved screening and awareness. Also patients more forthcoming.
*Yes, increased.(2)
*Unable to say for certain.
*Yes 1% more.
*2014 80.9 (Q4), 2013 83.7, National average 62.06
*Patients have requested screening more as more aware so yes.
*This has increased due to our quality improvement scheme. Patients with certain chronic diseases such as stroke/PVD or diabetes over 60 or COPD, Downs Syndrome records flagged to carry out tests if any concerns.
4b) Are patients raising memory related concerns with you at an earlier stage, and if so why?
*Yes, the subject of dementia is more frequently mentioned and

patients are asked routinely whether they have any problems, which is highlighting issues at an earlier stage
*Yes, more concern around memory, can investigate more quickly and reach diagnosis.
*Yes possibly due to TV coverage.
*Have not seen any particular increase. Practice has increased screening/prompts to patients. We have flagged patient records who have learning disabilities and other high risk groups.
*Yes carers are also raising more concerns. More awareness of the issue generally.
*Often relatives of patients raise concerns. Patients are often concerned about raising memory problems for fear of what the diagnosis may be.
Yes – More awareness
4c) Has the time it takes for patients to access the Memory clinic changed, if so please quantify?
*Waiting time increased due to volume of referrals.
*Don't know 4
*Couldn't say for certain but since start of enhanced service and quality improvement schemes relating to dementia, the number of referrals has most likely increased leading to longer waiting times.
*Patients referred are seen fairly quickly.
5) In your opinion, over the last two years, have diagnostic and subsequent treatment services for patients with dementia –
<ul style="list-style-type: none"> • Improved Greatly <input type="checkbox"/>2 • Improved a little <input type="checkbox"/>6 • Stayed the Same <input type="checkbox"/> • Have become a little worse? <input type="checkbox"/> • Have become a lot worse? <input type="checkbox"/>
6a) What steps have been taken at your Practice to improve staff awareness and understanding of dementia and challenge associated stigma?
*Included in staff training programmes
*All patients considered to be more at risk of memory problems have alerts coded to their records. This prompts clinical staff to carry out 6CIT test. All relevant staff receive required training to help keep them up to date with patient needs.

*Staff raise problems encountered. If changes in patient behaviour are noticed they are raised.
*Arranged training for reception and administrative staff in April 2016.
*Annual updates and regular discussion at Practice meetings.
*Using dementia e-learning package
We have recently signed up to have training for all staff to become Dementia Friends. This will run in 2016.
6b) Please give details of any mandatory training which clinical and administrative staff undertake around dementia at your Practice?
*All practice staff undergo Adult safeguarding training. The G.P's also have training in mental health capacity each year. G.P's and Practice Nurses also attend time out sessions on dementia. (2)
*E-Learning training has been undertaken by few. Will ensure all staff (including admin) undertake dementia e-learning in coming months.
*Yearly dementia updates
*Access online training via Time Out. Attend town wide training session for GP's/Nurses
*G.P's attend regular updates as required. All nursing and admin staff have access to electronic training modules and time to complete training
*Time out sessions, lunch and learn and dementia with lewy bodies.
7) What steps have you taken to promote the importance and benefits of early diagnosis and care?
*G.P's carry out cognitive tests routinely
*Posters/leaflets are displayed.
*Undertook the 2014/15 Dementia DES. Flagged with wall charts in consultation rooms.
*Increased screening/prompts to patients and flagged patient records in high risk groups.
*Discuss any problem with patient and relatives.
*Early intervention – diagnosis – treatment – better care
*We signed up to a quality improvement scheme aimed at facilitating early diagnosis and support for dementia patient.

8) What steps do you take to ensure that patients and carers are included in all stages of diagnostic and subsequent treatment pathways?
*Care plans are developed and carers identified
*It's been Practice policy to include patients and their carers in all stages of diagnostic and subsequent treatment pathways for better outcomes. We believe in providing a holistic outcome.
*Regularly update them with dedicated clinics at surgery
*Patients newly diagnosed are offered care planning meeting. Carer/family is offered health check if our patient to assess their needs. All patients with dementia are offered annual dementia reviews.
*Active involvement encouraged as with all conditions. Patient centred and specific to the individual.
*As part of the dementia care plan a named relative is included on plan. Patients attending for dementia review are always advised to bring a relative or friend to their appointments.
*Patients with firm diagnosis are followed up by Memory Clinic offered support.
9) How is ongoing assessment and care planning agreed and co-ordinated with patients, carers, memory clinic and other agencies?
*Emergency healthcare plans in place in home environment.
*Diagnosed patients attend yearly reviews of their care plans with named G.P. Practice has encountered some issues with secondary care agencies, often long waiting time to receive care plans from care homes etc.
*Patients are seen annually at practice or at home to review care plan along with carer or family member were appropriate.

10) What steps have been taken within your Practice to ensure your surgery is “dementia friendly” in the following areas -
Physical Environment
*We are a small surgery on one level, we use easy read signage to access clinical rooms
*New premises.2

*L.D/Dementia friendly signage
*Physical access to surgery is easy. Open access to G.P's means patients can be seen when needed.
Signage
*Easy read signage and leaflets are available.2
*We are working on it
*New purpose built premises2
*Posters in waiting room could be improved.
Appointment Systems
*Longer appointments if required with G.P. Also 30 minute health check with nurse for all dementia patients.
*Flexible timewise, and reminders sent.
*Extended appointments are available
*Fully triaged appointment system with phone/online access. Exceptions list for direct booking of patient appointments for those with other needs.
*Open access to G.P's
11) How do you ensure that patients with Learning Disabilities and sensory loss do not go undiagnosed and unsupported regarding the onset of dementia?
*Increased awareness, follow up complaints, clinical decisions
*Annual review for these patients with pro-active memory assessment if needed.
*G.P's have found it very difficult to conduct 6 CIT on patients with LD as they often don't understand the purpose of the test. Raising concern in next Practice meeting with LD team.
*Offered annual physical medical checks to patients with LD, opportunistic screening.
*Annual assessment3
*Patients over the age of 50 with LD have a flag on their records to show they are at risk of developing dementia. Clinicians raise this issue opportunistically and offer screening if appropriate.
12) Have you any comments or suggestions as to how diagnostic and treatment pathways could be improved in any way?
*Continue with awareness training for all.
*Early appointments at Memory Clinic.
*Improve communication and planning with other agencies, maybe

get together every three months and discuss patients.

Appendix 2 (taken from NICE Dementia Pathway guidelines)

