

# Living with Dementia - Forum Comments

Healthwatch Bolton

April 2018

This report is based on conversations or responses freely given by members of the public. Where possible, quotations are used to illustrate individual or collectively important experiences.

Engagement officers collect responses verbatim and we also present these in our final report as an appendix. This is important in showing the accuracy of our analysis, and so that further work can be done by anyone wishing to do so.

A full explanation of the guiding principles and framework for how we do engagement and analysis can be found online on our website [www.healthwatchbolton.co.uk](http://www.healthwatchbolton.co.uk).

*Please note that this report relates to findings observed and contributed by members of the public in relation to the specific project as set out in the methodology section of the report.*

*Our report is not a representative portrayal of the experiences of all service users and staff, only an analysis of what was contributed by members of the public, service users, patients and staff within the project context as described.*

Dementia is a descriptive term for when the brain's function becomes impaired by certain conditions. In most cases dementia symptoms will increase with time, though this timeframe varies with the individual.

Alzheimer's, Vascular, and Lewy Body are the three main types of dementia. It is also possible to have a mix of Alzheimer's and Vascular dementia.

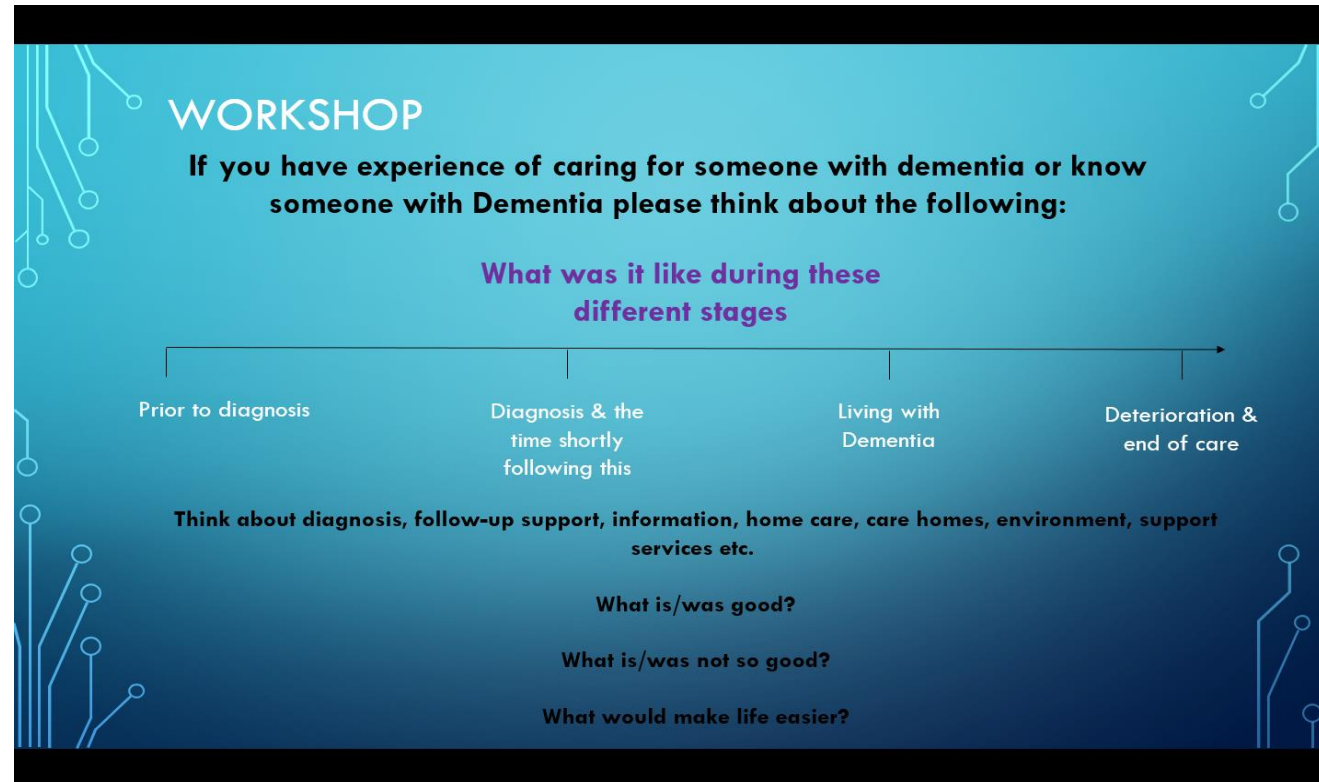
The usual effects of dementia are memory loss, altered speech, and impaired cognition. This can mean people experience personality changes, but their own understanding of this might be reduced.

Incidences of dementia are predicted to rise in the coming years, and though there is no cure for the disease, it is possible to assist both those living with dementia and any relatives affected.

This report looks at comments related to dementia from a local Healthwatch Bolton forum.

Reporting of comments taken at Healthwatch Bolton Forum – Dementia – 21/11/17.

Comments were gathered verbatim as closely as possible, or taken from comment sheets written by people at the forum.



**WORKSHOP**

**If you have experience of caring for someone with dementia or know someone with Dementia please think about the following:**

**What was it like during these different stages**

Prior to diagnosis      Diagnosis & the time shortly following this      Living with Dementia      Deterioration & end of care

**Think about diagnosis, follow-up support, information, home care, care homes, environment, support services etc.**

What is/was good?

What is/was not so good?

What would make life easier?

The slide features a blue background with white circuit-like patterns on the left and right sides. The text is centered and uses a mix of white and purple colors for emphasis.

Site	People	Comments
HWB Forum	35	87

\*5 people were HW staff

## Issues prior to a formal diagnosis...

- **Early signs/changes**

“We noticed he started doing odd things, like forgetting where he parked the car, struggling to cross the road properly, driving off without paying for petrol. If we had known these were signs we would have got help sooner.”

“He became quite childlike with his behaviour and would argue with people like he was a child on the playground. We know now this was because he was ill.”

- **Diagnosis**

“Fear (diagnosis)”

“Willingness to agree to formal diagnosis”

- **Solutions for diagnosis**

“Stay well check”

- **Communication**

“Lack of communication – people not knowing enough and services not sharing things.”

- **Power of attorney**

- **Living will**

- **Worry**

“Worry about family”

“Worry about others preconception”

“Financial worries – may also still be working”

## Issues on diagnosis and time after

- **Concern**

“Apprehension.”

“Feeling unsure about what happens next.”

“My experience as a carer was prior to a diagnosis and was one of frustration and helplessness. It effected my own wellbeing.”

- **Questioning**

“Who to go to?”

“What is the timeframe from diagnosis to follow up service?”

- **Reluctance**

“Family members can cover up partners dementia.”

“Person with symptoms is often in denial.”

- **Planning**

“Develop core plan.”

- **Power of attorney**

“Choosing POA?”

- **Service links**

“Staying well link with other services.”

- **Informing**

“Find out what is available for patient and carers e.g. Age UK very useful. Help available for finances and possible future needs.”

- **Communication**

“Making your own wishes known.”

“He wasn’t even told his diagnosis by a doctor. A nurse said it in passing. He wasn’t given any leaflets or contacts of local support services. We did not know about Dementia Friends etc. until right near the end, it was just too late then.”

- **Dignity**

“Double incontinence.”

- **Stigma**

“Stigma of talking to mental health team, stigma in family – prevents people from seeking a diagnosis.”



## Issues in the period just after diagnosis

- **Planning**  
“Person centred planning.”
- **Information**  
“People should be made aware of support services – benefits etc.”
- **Seeing a specialist**
- **Support**  
“Bolton Carers Support.”  
“Dementia Friends.”
- **Worsening health**  
“Contracting a secondary illness.”  
“Frustration of losing capacity/functional skills – effects emotional wellness.”
- **Concerns**  
“Fear of losing your dignity.”  
“Being respected.”
- **Poor care**  
“We had to change carers, the first company were terrible – not turning up or turning up late so they would get him up and give him his breakfast at 11am then come at 11:30am to give him his dinner.”

## Issues around living with dementia

- **Support**

“Bolton Carer’s support.”

“Bolton Dementia Support.”

“Dementia/memory cafes.”

“Singing for the brain.”

“Ongoing care support.”

“Carers assessment.”

“Dementia Friendly Café.”

“Dementia alliance.”

“CPN involvement.”

“Red Bag System (care home).”

“Allow person with Dementia to spend time with people – others with dementia.”

“Valued activities – music, something the person wants to do keeping someone as independent for as long as possible.”

- **Dignity**

“Incontinence pads were terrible, it took ages to sort out the right ones. We found out about ‘Kyles’ from one of the care staff, we had to fund these ourselves but they were fantastic and reduced his sores due to wetting.”

- **Poor care**

“He kept escaping from [the] ward at the hospital. He was on there because they had no room on the hospital dementia wards. The staff on [the ward] didn’t know how to manage his dementia. It made him more agitated and upset.”

“Recruiting carers who know what they are doing. They are on poor pay.”

“Issues with carers not knowing he had dementia.”

“Issues with Care line – if he had a fall they sometimes wouldn’t come out and he would be left for over an hour on the floor – why pay the money for the service if they won’t come. Or if they come and then say we can’t pick up because of our backs. On those occasions we had to ring 999 which was a waste of their services and also ‘what about their backs?’”

## Issues around living with dementia

- **Technology**

“Technology e.g. tracking when carers have visited e.g. tracking individual whereabouts.”

- **Concerns**

“Social workers not helpful.”

“Got help once I cried out for help.”

- **Information**

“Problems with obtaining information and withholding information.”

- **Communication**

“A member of my family was sedated at the care home without my knowledge. They were also left in care home and not taken to hospital after an incident without our knowledge. Why didn’t they call us and ask if we wanted her to go to hospital or not? That’s what should happen. If we agreed for them to stay at the home we could have

signed to say that. Normally they send them to hospital for everything which isn’t always required but surely the family members should be informed.”

“Every time we got sent to the hospital it was like reliving his diagnosis again. They knew nothing, why did they not know? He had a progressive, terminal illness, surely there should be some basic communication between services.”

“Needs one specific carer/home help to manage additional needs. This could improve communication, if only one person was in charge of filtering it down to others.”

- **Power of Attorney**

“Had issues sorting out benefits etc. No-one would speak to us because we didn’t have power of attorney. No-one told us about these issues when he was diagnosed, it caused lots of undue stress.”

## Experiences related to deterioration

- **Communication**

“Lack of communication between services.”

“Consistency of GP referral/assessments.”

- **Support**

“Marie Curie.”

- **Concern for family**

“Impact on family and friends.”

- **End of life**

“Great end of life care at Bolton Hospital.”

“My grandad at the end of life couldn’t communicate. I went to visit him in hospital and he was in agony. I marched up to the staff nurse and demanded to know why he had been left in pain. Her response was ‘he never told me’ I was fuming, he didn’t have the ability to tell her but you could clearly see by

looking at him. She didn’t even know he had dementia.”

- **Patient choice**

“Kept getting sent back to hospital when his wishes were to be at home. Caused undue distress to all family and patient. Had to argue with social workers to get him NHS care and bed at home.”

“Sometimes have restrictive visiting times – not good for families.”

- **Poor care**

“The quality of treatment was varied and out of area - Safeguarding issues - moved around without food and clothes.”

## **Issues prior to diagnosis**

People notice changes in a relative and worry over what this might mean/what to do about this. Those lacking a diagnosis might be concerned over the impact of dementia on their life, and avoid seeking a formal diagnosis. There might be questions about power of attorney and other legal issues related to an individual's wishes.

## **Diagnosis and time after**

Some of the concerns people had before diagnosis remained after dementia was confirmed. For example what were the legal implications of diagnosis? Some delayed diagnosis over concern over what this might mean. People were also concerned about the timeframe for when seeking a diagnosis. People thought it was important to make wishes clear at an early stage of the process.

## **Period after diagnosis**

Some people noticed they had worsening health during this period. Interaction with care agencies and networks of support increased after diagnosis. By interacting with care and health services there were at times experiences of poor care.

## **Living with dementia**

Many suggestions and experiences of dealing with multiple agencies and services. The challenges of retaining dignity and resolving the question of legal power.

## **Deterioration**

A need for services to communicate, to have knowledge of, be responsive to the needs of individuals who have dementia. Several people mentioned poor experiences of repeat transfers to hospital and poor experiences whilst in hospital.

*Healthwatch Bolton would like to thank all those that took part in this research or facilitated it to take place.*

**NHS Bolton Clinical Commissioning Group (CCG), Greater Manchester Mental Health NHS Foundation Trust, Bolton NHS Foundation Trust and Bolton Dementia Support's response to Living with Dementia Healthwatch Report**

We would like to thank Bolton Healthwatch for this piece of work and the subsequent report and for the opportunity to respond to their findings and recommendations. All of the aforementioned organisations did not have the opportunity to be involved in this piece of work prior to the report being produced, but remain committed and eager to working closely with Bolton Healthwatch in the future for Bolton people.

In addition, Bolton NHS Foundation Trust and Greater Manchester Mental Health Foundation Trust always welcome visits from Healthwatch to speak to patients, visitors, carers and staff, and encourage such opportunities. The only occasion where requests may have to be unfortunately turned down is in the interest of patient wellbeing if they are currently undergoing the acute phase of their treatment.

Involving all relevant services in projects such as this is important in ensuring the sample size increases and as representative as possible, and is also able to give a reflection of the current service. Substantial work has taken place over the last 12 months to develop our Dementia services for Bolton patients, which could result in the experiences of patient and carers accessing the current service potentially differing from the experiences from those who accessed the service previously.

## **Healthwatch recommendation 1**

*To the Dementia Partnership Board*

*1. To consider developing a strategy to streamline information about dementia, about dementia support and about dementia services so as to ensure that people receive consistent information in appropriate formats at the right time.*

### **Response to Recommendation 1:**

As part of the wider work of Greater Manchester Health and Social Care Partnership, a new initiative has been launched for Greater Manchester to transform the experiences of people living with dementia. The new Dementia United partnership has been developed to help achieve the region's plans. Dementia United are currently working closely in partnership with each area of Greater Manchester and have set the following nine key priorities –

1. Dementia Friendly Transport System
2. Lived Experience Barometer
3. End Of Life Care
4. Young Onset and Rarer Forms of Dementia
5. Mild Cognitive Impairment
6. Under-Served Populations
7. Post-Diagnostic Support

8. Prevention
9. Care/Residential/Nursing Homes

In Bolton, the five year Plan for Reform (Locality Plan) includes key focus on Dementia prevention and care in order to make a real difference to the lives of those living with Dementia. Bolton's multi-agency Dementia Partnership Board is currently developing a Dementia Strategy for the town, and through this Board, there is a multi-agency action plan which covers the whole Dementia pathway from prevention to end of life, incorporates the key priorities set by Dementia United listed above, along with local priorities that has been set based on patients' and carers' feedback and aligned to local needs. Through this Board, there is an on-going review of the Dementia pathway which is being reviewed by all relevant agencies and partners, and a Dementia Performance Dashboard for Bolton which is monitored every quarter. There will also be discussions about the provision of an inclusive, comprehensive directory on all services available for those living with dementia and their carers.

In addition to the above, Bolton requested funding from the Greater Manchester transformation fund to supplement local funding already identified to fully implement key transformation programmes required in Bolton. One of these programmes currently on-going is for the Memory Assessment Service to work closely with Bolton's Black Minority Ethnic (BME) communities to raise awareness of Dementia, build relationships, and ensure those living with dementia in these communities are diagnosed.



## **Healthwatch recommendation 2**

*To the CCG, Bolton Hospitals Foundation Trust and Bolton Local Authority*

*2. To ensure that staff in all services, in particular GP's, social workers, Careline staff, home care staff, ward staff and staff in A+E are dementia aware and able to respond appropriately to the needs of dementia patients and their carers.*

### **Response to Recommendation 2:**

There is a system wide approach to ensuring training and dementia awareness is raised across all various departments and staff, and is a key focus of the Dementia Action Plan. There are high levels of awareness amongst Bolton GPs as shown by Bolton's over 70% Dementia diagnosis rates which is higher than the average diagnosis rates reported nationally. In addition, Dementia care was discussed as part of a recent GP Education event at the end of 2017, and a detailed Primary Care suspected Dementia pathway for GPs is currently being developed.

Bolton's Dementia Action Alliance brings local organisation, groups and business together to improve the lives of people living with Dementia. Any organisations that is committed to improving their services for people living with dementia can join, and businesses such as shops, bus companies, taxi firms, police, fire and rescue, local authority, health organisations and charities

are currently part of the Alliance. A subgroup of this Alliance aims to have a coordinated approach to ensuring there is an increase in the number of Dementia Friends in Bolton, and have a targeted approach in signing up businesses and organisations to become more Dementia friendly.

A recent pilot in Horwich engaged with local businesses to create Dementia friendly communities, and will be rolled out across all of Bolton following the evaluation of the pilot. Greater Manchester Mental Health Foundation Trust (GMMH) also have a wide ranging training programme to help raise awareness of Dementia, and in 2016 delivered the CRADLES training to all front-line Bolton police officers which covered mental health crisis response, and also Dementia Friends training. Further training is currently being developed in conjunction with GMMH, Greater Manchester Police and NHS Bolton Clinical Commissioning Group (CCG) and will be delivered this year.

Bolton also has a Dementia specialist nurse in place who works across Bolton NHS Foundation Trust to support patients and their carers, along with ensuring all staff have the correct training and skills to enable them to meet the needs of their patients with Dementia. Bolton NHS Foundation Trust has also signed up to John's campaign which provides increased and flexible visiting and recognition of the importance of carers of those living with dementia. The Trust also holds an annual review of all Dementia work conducted across the Trust, which is then evaluated through their Dementia and Falls Steering Group.

## **Healthwatch recommendation 3 and 4**

*Local Authority, CCG and voluntary sector partners*

*3. To consider increasing the financial support available to popular and well liked dementia friendly support groups and services such as befriending, luncheon clubs and dementia outreach workers*

*4. Commissioners and providers to work together to explore options for a volunteer driver and / or accompanier service to support people with dementia to take part in activities where their carers are not able to attend.*

### **Response to Recommendation 3 and 4**

As an area, we fully appreciate the outstanding work and support our voluntary sector community undertakes, in particular to provide support to those living with Dementia and their families. NHS Bolton CCG is currently working together with local partners to look at the Dementia pathways and resources currently across Bolton to enable a better understanding of local provision to those requiring support. Bolton

Dementia Support is also exploring new ways in which to seek the views of those living with Dementia in Bolton, including those who have early onset of Dementia.

In addition, Bolton NHS Foundation Trust has a volunteer coordinator currently in post who is recruiting volunteers on an on-going basis, which includes supporting those with Dementia. The Trust also has an Enhanced Care coordinator who is working directly with patients with Dementia to develop therapies to improve their experiences and the experiences of the patient's family members.

As part of the Greater Manchester Dementia United priorities, Transport provision generally has been singled out as a key area by service users, and is included in Bolton's Dementia action plan. We welcome the suggestion of a volunteer driver/accompanier service, and we will work collectively to explore the options of such a service and the benefits to Bolton.

## **Healthwatch recommendation 5 and 6**

### *Voluntary sector partners*

*5. To consider developing volunteering opportunities specifically targeted at people who have come to the end of their caring role but still value the friendship and support of fellow carers and their carers.*

*6. To consider the establishment of a peer support group specifically for carers of people with dementia.*

### **Reponses to Recommendation 5 and 6**

Bolton has a multi-agency approach to end of life planning and care for all Bolton people regardless of condition, and has an End of Life strategy and multi-agency action plan which is aligned to the Ambitions for Palliative and End of Life care (2015-2020). Bolton NHS Foundation Trust also has a Patient's and Carer's Strategy in place.

As part of the Bolton Quality Contract within GP practices in Bolton, a carers register has been developed so that Bolton is able to fully support our carers. Bolton's Memory Assessment Service (MATS) currently advised the family of anyone who is newly diagnosed with dementia to ensure they contact their GP practice and be added to the register they can received the help, support and advice they may require.

The Memory Assessment Service (MATS) also has a service user peer support activism group called INSPIRE, which is open to both patients and carers

regardless of what/if any services they are accessing. This group has been widely advertised throughout Bolton and is mainly represented by carers. In addition, Bolton Dementia Support has a range of activities, events and resources available across Bolton to support people living with Dementia and also their carers. In particular, they hold a regular peer group meeting for carers of people with Dementia.

There is also a representative from the national Carers organisation TIDE (Together In Dementia Everyday) who sits on the Dementia United Steering Group at Greater Manchester level, who is very influential in involving and representing carers views. However, further discussion around support and opportunities for carers will take place at a future Dementia Partnership Board meeting.

Finally, for those living with Dementia and their families, Bolton Dementia Support and CVS' Community Asset Navigators are a point of contact if you wish to find out about any help and support available in Bolton. Also, the Silver wellbeing Service at Bolton's 1Point offers a bereavement and loss service which includes loss at a variety of levels such as role; relationships etc. and can provide talking therapies and counselling if required.