

Living with Dementia

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.

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 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.

Please see the 'related reading' section at the end of this report for further details and statistics on dementia.

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.

Engagement officers met with dementia patients and their family members at a variety of locations in the Bolton area. Due to the effects of dementia many people we spoke to had someone accompanying them.

Engagement officers attempted to speak to a variety of groups at the beginning of this research. We were unable to gain access to the hospital. Though we could not directly interview people at Bolton Memory Service, an information pack was left with them should anyone wish to take part.

This research was also advertised through the Healthwatch database, contacts, and those known to us.

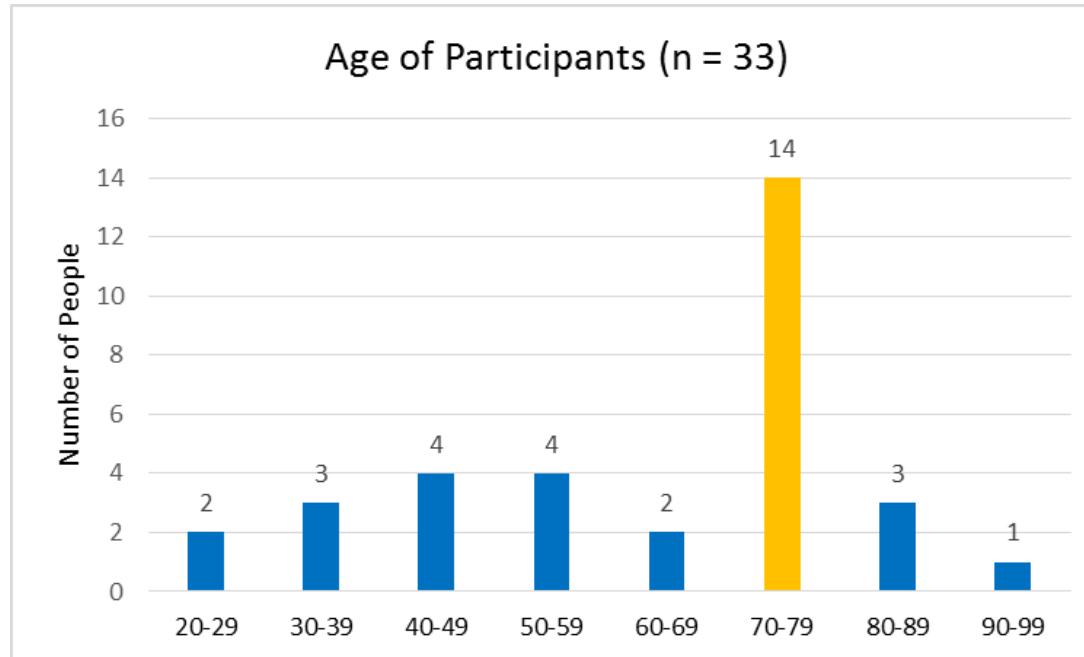
Interviews took place at Railways Men's Institute (RMI), Bar Lane, NHS Business Authority (PPA).

A key site for meeting those living with dementia are the dementia cafés. Dementia cafés are run by local groups as well as the Alzheimer's Society, they usually run once a month and allow people living with dementia to meet others in a safe environment. Engagement officers also contacted and visited local groups they have previously worked with, to see if this research was of relevance to them.

A semi-structured set of questions was used in conversations to ensure similar themes and experiences would be explored. Comments were gathered verbatim as closely as possible.

As part of this research engagement officers also spoke to agencies, these comments will feature in a separate report.

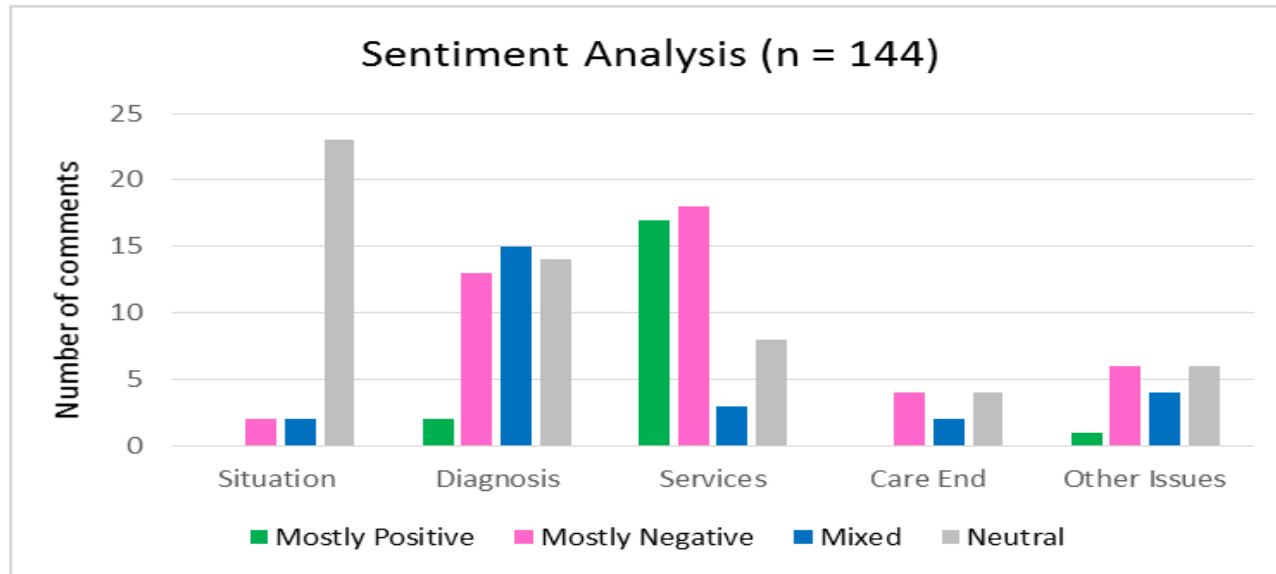
Event	Interviews	People	Comments
Interviews	10	13	52
PPA Interviews	9	9	53
RMI	5	5	21
Bar Lane	6	12	18
TOTAL	30	39	144



Ethnicity	
White British	31
White European	1
TOTAL	32

Gender	
Female	34
Male	5
TOTAL	39

- 30 interviews with 39 people present.
- Collected 144 comments in the interviews.
- Most participants were White British, Female, and over 70.



This chart summarises the broad comment sentiments in the five question topic areas looked at in this report.

We wanted to see if there was any link between the stage in a persons experience of dementia and their views.

Ultimately the results are reliant on people wanting to answer a question and also having had that particular experience themselves.

Comments in this case were not that easily comparable.

- Situation – most comments neutral, in line with this being a descriptive question.
- Diagnosis – comments were mixed between negative, mixed, and neutral.
- On services – there was an equal split between positive and negative.
- End of care – mostly negative, mixed, and neutral.
- Other issues – mostly negative, mixed, and neutral.

Comments Sentiment Summary					
	Mostly Positive	Mostly Negative	Mixed	Neutral	TOTAL
Situation	0	2	2	23	27
Diagnosis	2	13	15	14	44
Services	17	18	3	8	46
Care end	0	4	2	4	10
Other issues	1	6	4	6	17
TOTAL	20	43	26	55	144

Regarding access, we attempted to reach a wide range of people through channels already known to us, as well as exploring new ones. The research is limited however to those groups and individuals willing to participate.

Reflecting on the interviews, it was sometimes difficult to speak to people directly affected by dementia due to the effects of the illness, so we spoke to relatives when they were willing. The complexity of cases also means there was a need to listen to the many angles of the stories being told.

In terms of further research it might be worth exploring:

- If there are certain areas of Bolton better provided for than others in terms of dementia services.
- How the voluntary sector fits into the care and support arrangements for families.
- What place the internet, digital, and TEC has in dementia care.
- In this study the age of participants was quite similar, and participation from BAME was not very wide. It would be worth developing these two aspects.

Situation

- Having a family member with dementia places significant responsibility on families. Services do not always recognise this and people with dementia can often miss out on life enhancing opportunities as a result.

Diagnosis

- The journey to a formal diagnosis often takes some time, families often know beforehand due to signs and changes they observe.
- Relatives often fear a formal diagnosis and may not be willing to accept, or take some time to be convinced about having contact with services

Services

- All types of service providers need to have an understanding of dementia and the individual impact on families.
- People have more difficulty in accessing services when balancing working with care.
- Establishing trust in care agencies is time consuming and problematic for some.
- There is a lack of activities where dementia patients can be unaccompanied by a carer. This increases either the cost burden on individuals or the practical difficulties for family members and carer sometimes prevent people attending activities.

After caring

Relatives and carers routines are often closely bound to that of their deceased loved one and some continue to participate in activities long after their relative has passed away.

Situation

Types of dementia –

There were three types of dementia mentioned by respondents. Alzheimer's, Vascular and Lewy Body. Most people were suffering from Alzheimer's or Vascular Dementia, with many people just referring to the general term of 'dementia'.

Who is suffering –

The parents of adult children and partners of older adults were the main sufferers with a significant impact on all family members.

Where are they being cared for –

Either in their own home or in a care home.

Who is doing the caring –

Family relations as well as agency carers. Many families were making time to spend with their relation with dementia. These tend to be husbands, wives, and adult children.

"My husband has two sorts of dementia, Alzheimer's and vascular. He's had two strokes which he didn't know about until he had a third and a 'head scan' followed."

"I've been diagnosed with Alzheimer's; I don't know where it's come from. My husband had it and now I've got it."

"Dad lives on his own; I'm there everyday and I sleep there 3 nights a week. My brother and sister do the other nights."

"...There was a further decline in her memory and she wasn't managing at home despite carers four times a day. The family were helping but she still kept having falls. She didn't feel safe and wasn't happy going home from hospital the last time she fell and was admitted to hospital. She's not recognising anyone now."

"...I care for my husband; I do all the cooking, washing, shopping, all the bill paying; more so recently and I used to be able to ask him to go shopping but now he'll come with me but he won't go on his own. He comes with me everywhere. He won't drive now although I do drive. He will make his own breakfast..."

"I work full time and then go to my mums on a Sunday and sleep over. My sister and brother bear the bigger load; it falls mainly on them. I feel sorry for them. All her children work full time and have their own homes to care for. It's wrong that people have to pay and lose their homes; they've worked hard for them and my dad too. I grew up there. Carers Allowance is ridiculous; you can't manage on that."

Diagnosis

Diagnosis

Most people first contacted their GP following concerns about memory and noticeable changes. This led to a formal diagnosis, either through the memory service, or with a specialist.

Some people found the length of time to get a diagnosis meant they did not get help for some time. However the reason for a delayed diagnosis often seemed to be the creeping nature of symptoms, which took some time to cause concern. There were at times reservations by patients about seeking a formal diagnosis.

Emotional impact –

The need to care for a relative was often draining emotionally, due to the nature of dementia it often means watching a close relative worsen over time. For sufferers they might experience frustration at not being able to do as much as before, as well as needing to be reliant on others.

“The Memory Service at Lever Chambers carried out a two hour long assessment; they were thorough and good. We saw the consultant and two nurses and had really long conversations with them both. They spoke to both of us together and on our own.”

“As a family we knew something wasn’t right and we kept asking him to go for tests for about two years. He’d refused for a long time but finally did go to his doctor.”

“...We knew for ages, well had suspicions anyway but it was so hard to get a diagnosis. Not only was it long it was stressful. One of the hardest times of my life. In order to get a diagnosis you have to go to the memory clinic but my mum wouldn’t go...Because of this we never received any support. It was so hard and so scary.”

“I was devastated I could not drive anymore; it was my pleasure. I got a new car every year.”

Findings : What has happened since that diagnosis?

Support from services –

Many people experienced increased use of services and support services following diagnosis. This could mean people coming into the home environment to offer support, attending groups such as dementia cafes, time spent in hospital or care homes.

Deterioration –

As an effect of dementia people noticeably change over time and this can cause distress for relatives.

“We have had issues with family accepting the severity of the illness. It didn’t help that doctors would only speak to one member of the family. It was then up to that family member to spread the information amongst the family...We were repeatedly asked about ‘Do not resuscitate’ and repeatedly asked to sign documents about our wishes”

“After diagnosis mum was referred to a Dementia Advisor and we were told that she would be seen in about 2 weeks...In February 2016 we got a letter to say that due to funding the Dementia Advisor Service had been pulled; that meant we lost that connection.”

“What is needed is a bit more contact - there is a gap between the early stages and now when things are more difficult; we feel they’ve been left to manage.”

“He has delusions too so he’s growing his hair and his nails at the moment. He constantly questions things but he’s lost understanding. He says he’s got ‘dystemper’ and then he says he hasn’t!”

“...Mum was embarrassed and ashamed about her incontinence and if we’d had more information we’d have been better able to help her.”

“...she constantly empties the fridge, I go to cook something but she’s been there before me and thrown it away. Keys are a constant issue as she’s locked me out several times. She brings all sorts of things home from shopping, things that we don’t need...”

Services

Findings - Which services have met your/the person you care for needs since then?

There was a reliance on an array of services including healthcare, council, and support services; though not everyone uses all of these. There were positive comments about all of these services.

Health Services –

Include hospital, GP, nurses, mental health, and the memory service.

Council –

Include social workers, day centres, respite care.

Support Services –

Include dementia cafés, Age UK, care agencies, care homes.

“Our GP will come out to him and if I need an appointment I can get in more or less straight away.”

“We’ve seen the memory assessment service for several months; dad’s now discharged but we have a number to contact them.”

“After his hip replacement an occupational therapist provided aides; it’s been a very good service. Most items have gone now but he still has the shower stool yet.”

“Social Services were very good and supportive. They sent in a specialist team ‘when she was being quite aggressive’...They helped organise all the financial stuff to make sure we could pay. We thought we might have to sell our house to pay but they explained how it worked. They are very good but under resourced.”

“My grandad had refused respite care (for my grandma) once but my dad insisted he had it.”

“The dementia café is good and the Dementia Angels are there; it’s a good point to get information.”

“Can’t complain about the care home that look after mum. Probably not all are but ours is ok.”

Trust and Sensitivity

By nature dementia is isolating and makes people more vulnerable to mistreatment.

Due to the number of services required there is a need to have sensitivity; at times this was found to be missing, causing further distress.

“A & E staff are dreadful. Not all but they need dementia training. They don't know how to speak to them. A person doesn't need to go to A & E all the time. The care home have to call them if she has a fall... They have to call however they know that in a few minutes she will be right as rain.”

“Her family became concerned about her and rang the GP...The family have 'Power of Attorney' ...The GP was definitely checking what had been said by the family was correct. It caused my friend to be distressed and again to reject help from the medical profession.

“...I had to report a carer to our Social Worker as they were putting their own shopping in his basket when he went out and did his shopping. She asked my husband for £5 for petrol. I found out she was having her friends in our house whilst I was out. I noticed she was making herself food when she made my husband something...”

Reliability and communication

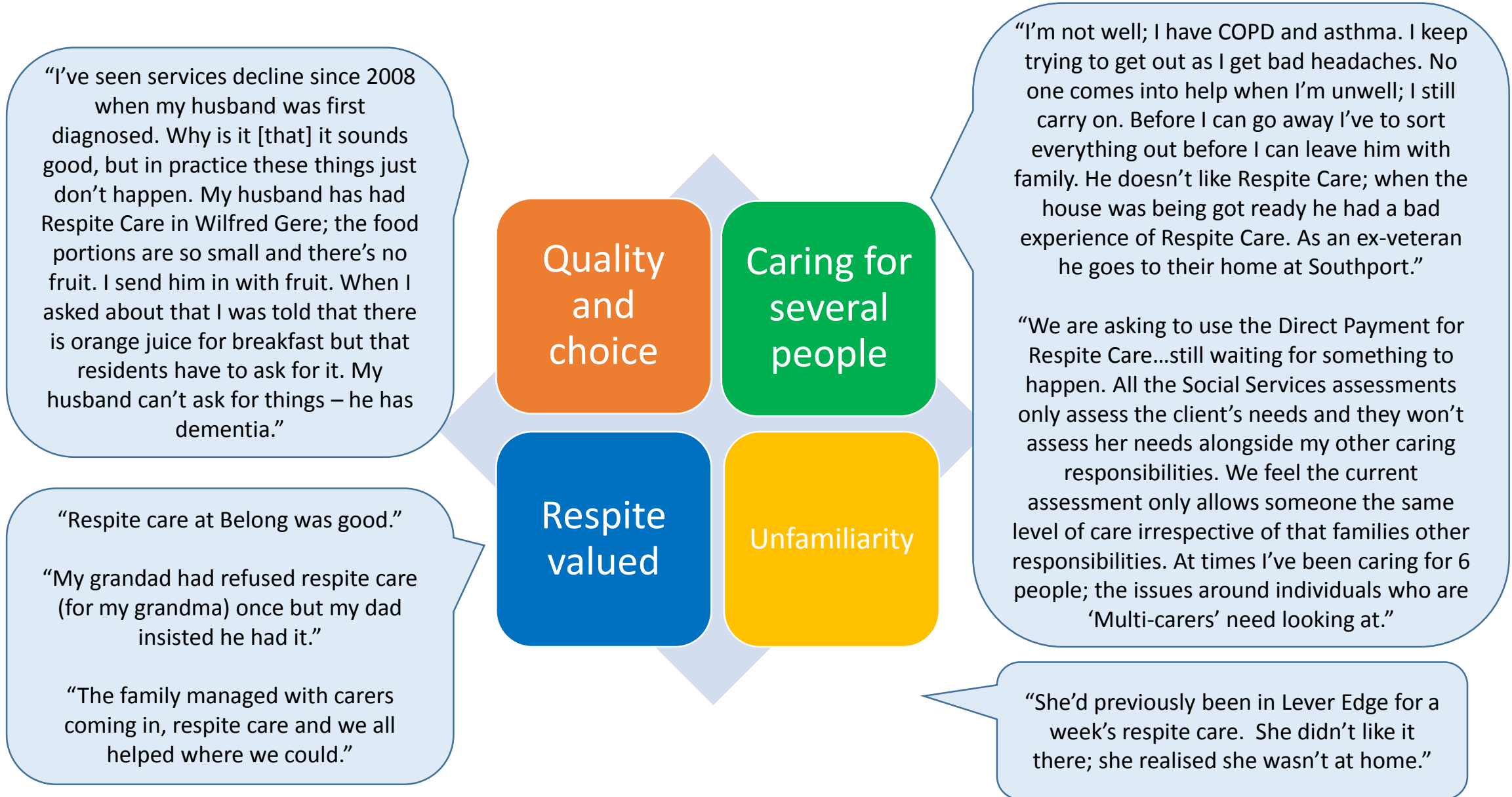
If key people at services did not turn up one day it might mean messages were not passed on.

Should someone be reliant on a small number of people, when that person was away this caused difficulty.

“When it snowed last her trip to the day centre was cancelled...not being able to reach anyone they left a message. As this was a last minute decision...so mum was left with no lunch after her breakfast and as she is diabetic we see this as a 'Safeguarding' situation...Keeping her safe is our biggest worry.”

“'Meals on Wheels' we found not to be great – the food wasn't up to scratch and the timing of the visits wasn't reliable; sometimes they would come late.”

“...approached Age UK about the 'Befriending Service'...No one came so I followed it up. They said they would be in touch and in the meantime here's a list of services you can access; another list of services!”



When Caring Ends

End of caring responsibilities –

Many were still caring for a person with dementia or did not comment on this question in the research.

For those that did answer they described understandable feelings of loss following the passing away of their relative from dementia. Many people had witnessed significant changes in their loved ones, which had also left an impact on them during the time of the illness.

Some continued to visit the support groups they had taken their relative to before, because they had become friendly with people there after using the service.

It might be possible to tap into this lived experience amongst those that have experience living with dementia, as some may be willing to re-train/volunteer/offer advice to others.

“We had no idea about how to come to terms with the changes when he died. Each person’s situation depends on the set up of the family and how the illness affects the patient.”

“It was difficult for dad to deal with what was happening to his mother. We say my grandma turned into something that she wasn’t.”

“I find that I can’t go anywhere where I’ve been previously with my husband. We used to dance but I don’t want to dance with anyone else.”

“I still come here for the support and friendship. My husband died seven years ago.”

Other Issues

Connect

People wanted to connect to others facing similar dementia related issues, and also connect to those able to offer professional advice.

More Community Support for the whole family

“A forum for families where families can meet and talk to others would be fantastic. I would love to have gone to something like that eight years ago when my mum was first ill. I just wish there was somewhere to go.”

“Could a member of the family [attend the] memory clinic instead if the person themselves won't go? Like I said my mum wouldn't go meaning we got no diagnosis and as such no support. If we had been told we could go as family members and speak to someone and get some leaflets at least this would have helped. Age UK were great but very understaffed, lots of it was leaflets 'take away and read yourself' sometimes you need to speak to someone and ask questions. It's such a confusing time.”

“For people newly diagnosed it's someone to walk with the family on an individual basis encouraging people to think about how life is going to pan out; group work isn't for everyone. Someone who could network among the dementia community.
An 'early on-set' Alzheimer's service.”

“She had lots of friends at the start but as she couldn't speak they were embarrassed. Mum was well known in her neighbourhood and had been for fifty years. There's a need for community support through a befriending organisation; we were told there was a waiting list for a luncheon club.”

In most cases dementia patients and their carers were balancing their responsibilities with other aspects of life. This was often challenging.

Many people praised the services they had encountered. In particular the GP and memory services were key to obtaining a diagnosis and giving patients/family the right information from the start.

On the other hand, the nature of dementia means it often takes some time to be identified fully. This can mean patients and families struggling, without knowing why changes are occurring in those undiagnosed dementia sufferers.

It takes time to find out about the services on offer outside the medical specialities, and a recurrent theme was the number of leaflets and amount of information being given out. At times there was too much information for people to understand, this may result in people not accessing everything available to them.

Services such as luncheon clubs and befriending could be oversubscribed, making them hard to access. But there are many benefits of providing these adequately, allowing relatives and carers a break from caring as well as people variety in their routine.

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.

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.

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.

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.

Alzheimer's Society

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

Dementia Statistics

<https://www.dementiastatistics.org>

Dementia UK

<https://www.dementiauk.org/>

UK Government action and announcements on Dementia

<https://www.gov.uk/government/policies/dementia>

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 receive 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.

1. Something about me and my situation.
2. How did you/they feel about that diagnosis?
3. What has happened since that diagnosis?
4. Which services have met your/the person you care for needs since then?
5. Are there services that haven't met your/the person you care for needs since your/diagnosis?
6. Experiences of those for whom caring has ended?
7. Are there any other issues which affect you/the person you care for wellbeing?

My mum was diagnosed with Dementia a few years ago and now lives in a care home. I'm [40s] years old am married and have 1 son who lives at home. For as long as possible we helped to look after my mum until she became too high risk. Her husband was also very poorly (he had cancer but never had an official diagnosis and never told anyone) at the time and found it extremely difficult. My mum had stopped looking after herself, not washing etc. wasn't eating and fell down the stairs on occasions. It was scary as we didn't know if she was ok, it was only until we would get a call in the middle of the night or morning from her husband that we would know if something was wrong.

I am a close friend of a person with dementia. Both of us trained together as nurses. I feel and I think that I am fully aware of the situation my friend is in and the services which are available. I have regular contact with my friend each week and other family members who share her care.

I care for my husband; I do all the cooking, washing, shopping, all the bill paying; more so recently and I used be able to ask him to go shopping but now he'll come with me but he won't go on his own. He comes with me everywhere. He won't drive now although I do drive. He will make his own breakfast. My aim with everything is to keep him active and happy which I believe will stop it progressing. From our experience of seeing other neighbours with dementia it's

when they stop getting out and doing things that that is when they deteriorate. My husband has two sorts of Dementia, Alzheimer's and Vascular. He's had two strokes which he didn't know about until he had a third and a 'head scan' followed.

We both care for my Mother (that's me her son and her wife). I do the paperwork and my wife is the main physical carer. We manage a direct payment for Mum.

It's 3 years since (family member) died, he was our grandad, dad and husband. He had had 3 minor strokes, heart disease and vascular dementia. He was unwell for 10 years. It started to be noticeable after his son-in-law died. The timing was difficult for the family who were also dealing with bereavement and some issues with foster children in their care. At the time they felt let down by Social Services and it all added to the upset at the time.

Mum lives in her own home with care from my brother and I. My brother and I are there overnight and look after her meals and running of her home. Mum has a form of dementia.

My husband has Lewy Body Dementia.

My father-in-law has Parkinson's and dementia. He's [80s] and his wife who cares for him is [80s].

My husband has vascular dementia resulting from a heart bypass 17 years ago after bad heart problems. He had the bypass 16 or 17 years ago in the June followed by a stroke in the July. The dementia stemmed from the stroke. He was kept in hospital for 2 weeks and then discharged home. He's had 3 strokes since and other TIA's (Trans Ischaemic Attacks).

I have been involved in caring for my grandma; she is currently in [care home in Leigh]. She was living alone but developed memory issues following a heart attack in 2016 when she had a pacemaker fitted. There was a further decline in her memory and she wasn't managing at home despite carers 4 times a day. The family were helping but she still kept having falls. She didn't feel safe and wasn't happy going home from hospital the last time she fell and was admitted to hospital. She's not recognising anyone now.

My mother-in-law has Alzheimer's; she lives at home with her husband in Horwich. She is just [70s] and she's had it for 2½ years.

Mum has dementia and lives in Atherton. She is [80s] and lives on her own; there is always someone, one of her children with her overnight. She's never on her own at night. Two of my siblings are her full time carers. She had a massive fall and cut her head; the hospital involved social services at that point. I sleep over on a Sunday night and I call Tuesday and Thursday night to make sure she hasn't fallen again.

Grandma passed away 3 years ago from dementia; she had Alzheimer's and Vascular. She had breast cancer and heart disease. She was unwell for about 10 years and we don't know how long before that she'd had the dementia – it could have been some time.

My mum has dementia – it's vascular. Her symptoms started in 2014; she kept repeating herself, her sleeping pattern changed. I saw her every day; her personal hygiene was noticeable. She was [70s] when she started and now she's [70s].

My mother-in-law and father-in-law both have dementia; it's Alzheimer's. They were diagnosed 18 months ago. Since then my father-in-law has tried to kill himself so was sectioned and after a stay in Woodlands is now in a care home. My mother-in-law is living on her own with carers visiting 3 times a day. She has broken her arm and whilst having an operation to repair the break picked up hospital pneumonia and is now in Intermediate Care.

Mum lives with me and has been diagnosed with dementia. She is [70s]. I noticed changes around memory issues but felt she had experienced a difficult time with the loss of a good friend and her husband which had meant she had been lonely and her days were long. She had had two brothers with dementia. I mentioned it to her GP who said to "keep an eye on her". She had me up in the night 3 times needing an ambulance as she felt it was her heart; I later found medication that she hadn't been taking.

Nan has it (dementia) – she was diagnosed 12 months ago but the family have been aware of changes for [x] years. I visit Nan now in a home in Widnes; she’s now [80s].

Dad lives on his own; I’m there everyday and I sleep there 3 nights a week. My brother and sister do the other nights.

Mum had a stroke in 2006 and then in 2010/2011 she had a diagnosis of Vascular Dementia caused by the stroke. She was [70s]. She couldn’t speak; she’d had speech therapy. After her stroke she lived independently but we started to notice she couldn’t remember how to make a cup of tea without being prompted.

I looked after my wife at home until she went to Firwood one day and someone told me I couldn’t do it anymore. She died quite unexpectedly one day; they phoned me up and I contacted my daughter in law so I managed to be there when she died.

I’m caring for my wife.

My dad has dementia

My husband had dementia and died last May. I still come here as I’ve got to know everyone and its somewhere to go.

I have had dementia for 12 years now; I am registered blind now for 6 months. I am happy in myself. I like singing and dance in a fashion.

I care for my wife – she’s [80s].

I’ve been diagnosed with Alzheimer’s; I don’t know where it’s come from. My husband had it and now I’ve got it.

I look after my husband who has dementia

Diagnosis – length of time it takes to be diagnosed. It's too long. We the same illness and they'd chat and remember things but he now knew for ages, well had suspicions anyway but it was so hard to get a diagnosis. Not only was it long it was stressful. One of the hardest times of my life. In order to get a diagnosis you have to go to the memory clinic but my mum wouldn't go. At first I think it was her fear but as times went by (years) she just heard the name of the service and refused to go. We tried to say it was called something different but it was too late by then. Because of this we never received any support. It was so hard and so scary.

She knew she had something wrong with her but she avoided accepting it was dementia. The first time anyone spoke it, or wrote it, was (no one mentioned it) was when the domiciliary psychiatrist wrote to her GP and copied her into it. That was the first time anyone had used that word. She knew what that word meant; we have assumed it is Alzheimer's due to the medication she has been prescribed. The rest of us knew or suspected what the diagnosis would be.

As a family we knew something wasn't right and we kept asking him to go for tests for about two years. He'd refused for a long time but finally did go to his doctor. We were both absolutely devastated. We went to Lever Chambers and didn't ask much when they told us; you sit there and you take it in but it wasn't till we got back to the car that we both cried; we were both in tears. It's a horrible disease with no cure; it's worse than cancer. He used to visit a friend with

We've just been to another friend's funeral who also had dementia.

We took my mother to her GP after the family had noticed changes to her short term memory. It was the way she was looking after herself too that concerned the family. There had to be a brain scan done as, to the world, there wasn't a problem. She had had a stroke affecting a particular part of her brain. She tricked us at first as she could, and still can have, a conversation with you but 10 minutes afterwards she's not remembering anything from that conversation. She remembers family but not as they are now as they've changed and grown up. She doesn't know what's happened to her as she can't remember having had the stroke.

Dad said "I can't believe it" but we saw little things that others missed or were attributed to other things. He left his car on Asda car park and walked home as he couldn't remember where he'd left the car. He had been hoarding things; there were personality changes; changes in how he communicated and how he connected with older memories. Dad wasn't well and we took him to the old 'out of hours' place at Landmark House and saw the emergency doctor. He was told he had heart rhythm problems and vascular dementia. He saw a consultant who said he was terminally ill with heart disease and the dementia; we were told he would live 2 years but actually survived for 10 years.

Mum's words:-"They can't do any better or any more than tell me you're suffering from whatever" " When they told me "I came home I would sit outside and talk to myself; I've fought a good fight and run a good race as St Paul says and I'm waiting to be called home. the years go on I don't complain. I've been a nurse and have nursed people with dementia. There's not a lot anyone can do you have to accept it and do what you can yourself. I talk to myself a lot and tell myself these things.

Daughter's words:-"The Memory Service at Lever Chambers carried out a two hour long assessment; they were thorough and good. We saw the consultant and 2 nurses and had really long conversations with them both. They spoke to both of us together and on our own. I had some time with the nurses whilst mum went off and did some tests. I started to cry and Mum asked me why I was crying? She said it should have been her crying! mum handled it brilliantly."

He went to the GP when he was about [60s] and was just told he was getting older. It was a psychiatrist that said it was dementia and then 4 or 5 years ago they decided it was Lewy Body Dementia. Up to then he was treated for Alzheimer's but now he has delusions which need different tablets.

My father-in-law now has heart disease and feeding issues. He has a feeding tube now in place. Unfortunately he has a second bout of pneumonia and is in hospital in Bolton. His wife had to stop a

member of staff trying to leave him a cup of tea. They didn't realise that he shouldn't have anything to eat or drink. His wife has acknowledged the amount of information she has been given but it's as in lots of leaflets and so she doesn't know or is mixed up about who to contact for support or when. The leaflets have just been thrown in a draw.

My husband says he's not got it. "They've got it wrong" he says. My husband is only [70s] now. There is no dementia in his family but there is heart disease.

I have been involved in caring for my grandma; she is currently in Bedford House Care Home in Leigh. She was living alone but developed memory issues following a heart attack in 2016 when she had a pacemaker fitted. There was a further decline in her memory and she wasn't managing at home despite carers 4 times a day. The family were helping but she still kept having falls. She didn't feel safe and wasn't happy going home from hospital the last time she fell and was admitted to hospital. She's not recognising anyone now.

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Mum had a stroke in 2006 and then in 2010/2011 she had a diagnosis of Vascular Dementia caused by the stroke. She was [70s]. She couldn't speak; she'd had speech therapy. After her stroke she lived independently but we started to notice she couldn't remember how to make a cup of tea without being prompted.

Well I took early retirement to look after him; I lost [regular salary] and now I find I can't get Attendance Allowance until he's been unwell for 6 months. How can that be as for months he's obviously been unwell and ringing me at work, in the middle of lectures which made my job impossible.

We've not discussed his diagnosis with him; we've not used the word Alzheimer's.

I was devastated I could not drive anymore; it was my pleasure. I got a new car every year.

Well I don't understand why I've got it. They did a lot of tests and told me that's what's wrong. They told them I had Alzheimer's before me; they knew before me. I've had a lot of falls so that is why they found out.

Dad has been struggling for the last 3 years with no help from anywhere. I struggle not having a day off looking after him.

It would be useful to have support for family incl. expectations of how the illness works, prior warning of things that might happen e.g. panic attacks. I've never had any experience of panic attacks so when it happened I didn't know what it was (I rang the doctor and explained how she presented and was told 'Well that's just a panic attack.' She was rude and dismissive. I said well sorry I have never seen anyone have one before and didn't really know what I was looking for and I never expected this to happen, she's never had one before. If I had been given some information about some of the signs and symptoms I wouldn't have been as shocked), characteristics of the illness, things to be aware of, where to go for help, I've never heard of a memory café (this was a comment after a mentioned a memory café), I didn't know about memory clinics, they won't diagnose without going to a memory clinic and she wouldn't go. I didn't know about anything about benefits, POA or places of support. Knowledge of all these things would have been so useful. It's such a cruel illness. My mum has Vascular Dementia & Alzheimer's. Its contradicting as one means a slow progression and the other means quick. It can be really confusing. She is my mum, my world and suddenly she was collapsing in front of me. She didn't know who I was, she thought she was a young women living in Scotland (where she is from but has lived in England for over 60yrs) I remember just crying because I didn't know what to do. I felt like I asked so many people for help and no one could give us the correct information. If someone could have just sat with us as a family and explained things then we could have supported one another and her.

When we were first looking at care homes. Oh my god this was tough. I had so many feelings. I felt guilty for even thinking I was saying she needed to go in a home. It was one of the most difficult times of my life.

I felt guilty. I was just cast away to find her support. Mum is now in a care home and has been for 8yrs. There are so many homes but all for different things. Initially we went somewhere and even picked a room but then they said 'sorry she can't come here as this is a nursing home and she needs a care home' we didn't even know what the difference was. Why couldn't someone have told us that at the start? They knew we were coming to look around and just let us despite her never being able to go there. Can they not have a criteria list that family can have so they know what type of home a person requires? Also this would be useful for knowing when she needs to transfer. You transfer to a nursing home when they need nurses due to illness. If you just have Dementia or Alzheimer's you don't necessarily need this. I do worry though. In terms of assessing if her needs can be managed in the care home. Not long back I had experience of this. She was really incontinent, wetting herself all the time, she was smelling and getting sores. They take her for a wee every hour but she will still come back to the chair and wee. She is then just sat in this wet until they come to get her up again an hour later. It's awful and so sad. She would hate it. She was such a proud woman and so fit and healthy. She used to walk into town every day, it helped keep her fit. She was tiny, a size 8, now she is a size 20. She is swollen everywhere. She won't have her hair done, and often won't wash. I asked the question can you still look after her. She is doubly incontinent and at night too. I had to ask for a meeting with the manager to check that they can still manage her care. The manager is lovely and she said they were still ok managing her care. Its only if she became medically ill in a different way or if she became violent that she would need to move. At the beginning you're going in to it blind.

My friend lives in a house on her own. One of her sisters takes care of her personal hygiene and other family and friends look after her shopping, social life and cooking; there is an 'Enduring Power of Attorney' in place. We feel she is slowly deteriorating almost plateauing and then you notice something getting worse again. She is calmer when one particular member of her family is around. She just has no retention and is constantly searching for her key. She offers you a drink but can't or doesn't know to boil the kettle. She sleeps in now and often isn't ready to go out until 2pm.

One of her family was a midwifery sister and she took early retirement to help with my friends care.

I am seeing a deterioration in him. On 2nd January just gone he woke up unwell and I rang his GP. He'd woken up with a slight droop to his face and some numbness in his arm; the GP told me to ring for an ambulance and get him to A&E. I took him and we were there 5½ hours whilst they took a blood test and did a scan of his head which had been requested by Salford Stroke Unit. He seemed better and got the feeling back; they discharged him home and we're now waiting for an appointment at the TIA Clinic at Salford. That appointment will happen at Salford which I'd rather not drive to as it means a motorway journey; I'd rather drive anywhere than there. I'll have to ask friends or family to take us. That's how he knew he'd had two other strokes following that 'head scan'. Because it happened at night he's now worried he'll wake up in the morning and have had another. I've told him he must wake me up if he's not well and we'll get help straightaway rather than waiting till I wake up.

She lives in 'sheltered accommodation' with a warden although the warden isn't there all the time. We do all her shopping, plan her medication, getting her to her medical appointments and her safeguarding. She has carers who come and put her to bed; we think she is slowly deteriorating as her memory board has gone from a weekly 'what's happening' to a daily display. She won't go outside now without a carer. Some of what she does happen in the sheltered housing and they miss her if she isn't there. She can add up and read still but then can't remember which makes her very vulnerable. She now needs new two knees and a new hip but consent would be an issue and she wouldn't understand or remember what to do in her recovery. We worry very much that her mobility will be affected and for her future.

We were given no information; we looked everything up ourselves and other people would tell us things. Our first thing was to deal with the hoarding as I knew he wouldn't be able to stay if his house wasn't cleared out.

He's had pancreatitis three times and because antibiotics were administered badly we were told he could die and that we could sue if we wanted.

We have had issues with family accepting the severity of the illness. It didn't help that doctors would only speak to one member of the family. It was then up to that family member to spread the information amongst the family. There was a lot of pressure at the time living with the illness and the family's reaction; every time he was very ill there was a bad reaction from the family. We were repeatedly asked about 'Do not resuscitate' and repeatedly asked to sign documents about our wishes

After the diagnosis we've been discharged back to the care of mum's GP. We haven't been a lot; they're ok. We don't tend to see them a lot. Mum has a named GP but if mum is unwell we would see any of them. The last time we saw one we were with them for 40 minutes. The GP was obviously a trainee and kept 'ping-ponging' between us and a more senior GP asking them what they needed to know. Mum feels they can't really do anything though. After diagnosis mum was referred to a Dementia Advisor and we were told that she would be seen in about 2 weeks. That was in June or July 2015. We saw the advisor in September 2015 who was lovely. She gave us a pack of information. In February 2016 we got a letter to say that due to funding the Dementia Advisor Service had been pulled; that meant we lost that connection. Mum's words – "Those things are important; I can't see why I can't have someone like that from the Memory Service; even if you can't see them and don't need them you know they are keeping an eye on you. That's valuable. You wouldn't leave someone on their own with another brain problem something like meningitis.

He was active up to his diagnosis; he became very upset as he was just coming into retirement age. He was not going to be able to do what he wanted to do. We've had most information from 'Facebook'. We know there is a local support group but my husband is happy at home and won't go out far now.

He's had suicidal thoughts and took tablets and a knife with him to the day centre.

We've moved now – he chose where we live now.

I'm worried a little about his DLA claim.

He has delusions too so he's growing his hair and his nails at the moment. He constantly questions things but he's lost understanding. He says he's got 'dystemper' and then he says he hasn't!

He likes to occupy himself with making models out of matchsticks. It keeps his mind busy. I don't think he's seen an Occupational Therapist.

She went into Bedford House in Leigh and developed a water infection. They sent for the doctor who diagnosed dementia. The doctor used the blanket term of dementia. She has a few lucid moments but most of the time in the home she, in her mind, is living in a time when she was a little girl. As she is able to look after herself in the main, she isn't in the Dementia Unit there.

There's been a few visits from the GP which have been attributed to a water infection caused by her incontinence. The home always contact my mum and dad, as her next of kin, mum and dad feel that the staff know what's going on for grandma, notice how she is and feel reassured about her being there. They feel happy that she is in the best place.

It's now 2½ years later and he's not coping. The other son has become concerned and contacted Social Services to find they weren't on any sort of list for help, support or further follow-up. They've slipped off the radar; no one is there to help. Now the social worker is involved there has been encouragement to attend the Dementia Café which is good to a point and they know about the 'Dementia Angels' which is useful because she can get lost. Its not always her wandering off, sometimes he can loose her; he managed to get on a bus home from Manchester without her which was distressing fro everyone. Her husband doesn't let us do a lot to help. What is needed is a bit more contact - there is a gap between the early stages and now when things are more difficult; we feel they've been left to manage.

We used to have carers to help get her up but she wasn't being cleaned or cared for properly. I was in the house once and heard them come in ; I stayed upstairs to see what they did. Out of a half hour visit it took them 10 minutes to come upstairs to Mum. Mum needs a shower every morning; the carers left dirty clothes lying about and dressed Mum in dirty clothes. Her family now care for her 24 hours a day.

The family managed with carers coming in, respite care and we all helped where we could.

Grandad hid it from us; I don't know how much he passed onto my parents about what was actually happening.

Two weeks before he died he said he admitted he wasn't coping; he

took his marriage vows very seriously - "Till death us do part" and "In sickness and in health"

My mum's partner wanted her at home but she's now in Rivington View since about 3 weeks ago. She has now been diagnosed with bowel cancer; we didn't pick up on it because of the dementia. She is deteriorating. So far so good at Rivington. She'd previously been in Lever Edge for a week's respite care. She didn't like it there; she realised she wasn't at home. She went into Hazelbrook in Oct 17 for two weeks but came out with a water infection. It may have been due to her incontinence I don't know. Mum was embarrassed and ashamed about her incontinence and if we'd had more information we'd have been better able to help her.

Communication with my mother and father in laws is heart-breaking; it's knowing what to tell them as they don't remember anything. His attempted suicide ended up with him in A&E; he was in Woodlands ward for 7 months with varying levels of confusion. He was on a male only ward and then moved to a mixed ward but had to be moved back to the male only ward. Now he's in the care home we visit him there. The care home had taken him out on Sunday and when we visited him we found him anxious and fearful; in fact I'm troubled by how we found him. He can still act that he's ok when in fact the staff don't seem to pick up that he isn't; he tells us when we visit him.

Her next appointment is at the Memory Assessment Clinic is January 18th for further assessment so I'll mention all the things that I'm worried about there.

There are a lot of things that affect my mother and consequently myself; she constantly empties the fridge, I go to cook something but she's been there before me and thrown it away. Keys are a constant issue as she's locked me out several times. She brings all sorts of things home from shopping, things that we don't need or that we have already several times. I now brief the person who goes shopping with her about what we need. She constantly asks me questions and can't retain what I've told her. I don't know what she's understood and I'm terrified what she will tell someone ringing on the phone in case it's a scam! I have 'Power of Attorney' as she was forgetting and mixing up her PIN number although I wanted her to have her independence as far as her money is concerned. She's also now started hoarding things like magazines.

She was kept in hospital in a dementia unit in Whiston for about 2 months. She then went into a care home with a dementia unit but kept escaping. Then she was sectioned again and went into another home with a secure unit. It's a lot better for her although she can't walk now or know who we are. She's more calm now but that might be due to medication. Her speech is confused.

"She was in a home for 3 months before she died. She went downhill and was found in a chair when we walked in to bath her. She was sat in her own chair in her own room; it looked like a haemorrhage of some sort.

She was taken then into hospital and never came out. There was no explanation from the hospital, Salford, as to what had happened apart from being told it was probably an ulcer. We were invited to things like dementia and stroke awareness but it was in the day time and we were all working."

We've got a file of information which is quite fantastic but its hard work going through it.

What I've managed to find out as come as a result of me pushing ourselves forward. I worry for those people who can't push themselves forward or ask for information.

I've been told to contact Attendance Allowance people after Christmas as I've got to wait until dad's been diagnosed for 6 months even though he's possibly had it for a while and it's not going to get better. The Memory Service have actually said I should be getting it but that isn't what's happened yet.

He's had a fall and I think after that he has deteriorated.

My wife has been by my side to help me.

We had the course by Bolton Memory Service but since then nothing until my wife has been referred here to the café. She wouldn't come at first but I just brought her and now she enjoys it. She's also going to a day centre now. We're going to get a visit from the Integrated Neighbourhood Team, I think they are.

I've had a lot of NHS people coming, everyday they're bringing me something. I've got a chair now; I didn't know they were coming. They speak to my son and daughter first about everything.

Dad goes to day care 2 days a week to Thicketford. I've had Attendance Allowance and Carers Allowance for the past 3 years. I feel we've struggled for the first 3 years without knowledge of these groups (Dementia Cafes); Dad goes to the Victoria Hall café too.

Social Services were very good and supportive. They sent in a specialist team 'when she was being quite aggressive' they were an urgent support team. The care home flagged it to Social Services and they got them involved. Social Services are very supportive but I don't have much connection with them anymore. They helped organise all the financial stuff to make sure we could pay. We thought we might have to sell our house to pay but they explained how it worked. They are very good but under resourced. The people in the homes – well most of them Can't complain about the care home that look after mum. Probably not all are but ours is ok Dr's are very hit and miss. Ours was very unsympathetic and fobbed us off all the time. We had to change. Now the GP is good. Paramedics are great

My friend never went to the Memory Service as her GP, (DR), did the full test himself; he didn't refer her to the Memory Service. He spent 30 minutes with her and did the memory test with her; I was there and he was very proper about asking her permission to do the test in front of me. He did refer her to the Community Psychiatrist who kept writing to her to make arrangements to come and see her but she responded and said I don't want to be seen. 3 or 4 months later she was allocated an Occupational Therapist via the Community Psychiatrist who hadn't seen her. The Occupational Therapist came to the house 3 or 4 times but my friend and her never established a

line of communication.

My friend initially refused medication because she said there was nothing wrong with her; she still has not medication.

She and her close family member attend one of the Dementia Cafes which both of them have found enjoyable and useful. It's the one place he's found to be helpful. The person who takes her thinks she thinks she's a nurse there; she talks to the other people there because she thinks she can help them. There's information available there. Someone called (name of information holder) is going to see her tomorrow but we're not sure who she is or where she's from. Her family will be there tomorrow.

The staff and the care at Bolton Memory Service have been very thorough and recently have got my husband's blood pressure sorted. He was prescribed some medication early on which didn't agree with him but they seem to have found something now, Gulantamine, which he seems ok on. As he's ok they've discharged him back to his GP who isn't that brilliant. We'd both rather him be seen by the Memory Service even if it was on a 12 month basis. The Memory Service told us that discharging him back to his GP for care is because of the demand for their care when you need a diagnosis. The 10 week course we did after he was diagnosed was brilliant; there was lots of information; I'm still going back to the pack they gave me and following up things. They had speakers and a solicitor came who gave lots of information; it was really helpful. My husband goes to a gardening club [at location] which is due to start again in February; that is something he really looks forward to. I try to find him things to do to keep him active. We've been to a production at the Octagon which was dementia friendly and they've promised more. The cast came and spoke to the audience afterwards; it was really good. I'm going to try and find a Singing for the Brain group as he seems to enjoy music more these days and I'm going to look for a chair based exercise group. I think I've been given information about those groups.

needs. She goes to Winnifred Kettle Day Centre which she likes; they come for her and bring her home to her flat. She attends 'Senior Solutions' lunch club. A fish and chip club but all these voluntary things stop over Christmas and it's over to us then. We pay for extra activities.

We use technology to support mum at home; it goes to my wife's phone so we can know how things are for her all the time. We find it really helpful and reassuring. We call it our 'Nanny-cam"! We keep saying to her that she has the camera in her house and she seems accepting of it.

He went onto either J1 or J2 and was more settled where he had further assessments to help him to get home.

The hospital bed was collected very early after as it was in need.

The church around the corner has invited mum to their fortnightly lunch and has offered to pick her up.

Mum has a neighbour who comes in and they share conversation about their faith; the neighbour's very good and will make mum a drink.

We use 'Your Choice' Care Agency who cover 3 visits most days and 4 visits on another. They are very good and understand my mother's

- The second GP we've seen has been sympathetic.
- Mental Health Practitioners
- Bolton Older Adults Community Mental Health Team – they've been fantastic. He's down for a 6 month review unless there's any worries before.
- The Memory Service organised an appointment with a dietician
- The Social Worker has been really good. They do whatever they can to help.
- We have a good family who help to look after him. I don't know how people without good families go on.
- Occupational Therapy have been round and supplied some things to help
- The Social Worker is getting the physio to strengthen his legs as my husband says he wants to get out. My Social worker is excellent. I'm offered emotional support if I need it. If I was stressed about my husband I would contact her and I know she would come straight away. I was taken to Prestwich for a dementia awareness day which was excellent.
- Now he has carers from XXX agency and they are excellent; I couldn't ask for anyone better. My husband needs the same carer as he gets confused. When she's off I won't have anyone else.
- Our GP will come out to him and if I need an appointment I can get in more or less straight away.
- There are lots of different practitioners coming in;- a dietician,

district nurses, social worker, chiropodist and carers 4 days a week. They take him out; he used to go to the Jubilee Centre. Now he doesn't want to go anywhere or go out; he went to Firwood in the past which is now shut. He goes to Thicketford now but says he doesn't do much.

- The District Nursing Service said they've now got his problem under control now and that other people need them more.

Bedford House is ok. Since she's been in there her mobility has improved. She's gone from two person support to managing with one person now. Her weight has been increasing too as we weren't sure when she lived at home how often she was eating. She seems happy enough in Bedford House so we feel the home is ok. They play games with her; there a activities like singing which they seem to enjoy. I visit her twice a week and I notice that her nails are painted and she's in her own clothes. There is the option to do her own washing; there are a few things that have appeared in her room which aren't hers but nothing of hers has gone missing. The care staff are ok. The family are happy.

She has the Dementia Angel if she goes missing and she has something on her phone to help.

The Social Worker provided a clock and gave us information about organising a sitter so Father-in-law can get out on his own or to take my Mother-in-Law out but they're on a waiting list; they've been waiting a few months now.

My Mother-in-Law sees her GP regularly for other illnesses; she had issues with eating and would spend a long time cutting food up into small pieces which interfered with her eating; her GP persuaded her to eat better.

The Dementia Café is good and the Dementia Angels are there; it's a good point to get information.

Respite care at Belong was good.

The family have gone to Age UK for help and advice.

Dementia Cafes would have been a great help to my grandad and grandma; for grandad to have been with other people who were experiencing what he had been experiencing would have been good. They weren't around when they needed them.

From what I can remember care was good. My grandad had refused respite care (for my grandma) once but my dad insisted he had it.

Grandma threw water or tea over someone whilst she was at Firwood Day Centre and they sectioned her. She was admitted to 'J' block for assessment whilst they sorted medication out. Then she

went onto a nursing home under "extension" from the hospital to Mill View. She had excellent care at Mill View; they were angels, amazing. She was in Mill View for [many] years and died on the day she went in there, [10s].

She's been into hospital 3 times this year and onto E4, E3 and C2 with the bowel problem mainly investigating the pain. Eventually Mum was able to have the procedure after there were problems around the iron medication but finally they were able to see and diagnose a bowel cancer.

I had written information about Dementia Cafes but mum has said she doesn't need to go.

The secure unit where she is currently is amazing. There's a bar with soft drinks, dances, music and crafts. Nan likes activity, places and space to wander. She's always walked as she never drove. Her hair is done in the home.

Social Services always took my calls and always rang back. It wasn't always the same person and they helped with Assistive Technology to monitor mum. We had to enquire what there was to help and it had to be initiated by us.

I found out about the café through the file of information. I found out about the sports activities at the Arena for people with dementia by chance. There should be an increasing use of the cafes to let people know what's going on. There needs to be a timetable detailing opportunities for people living with dementia.

Tuesdays I go to Thicketford Centre in the morning and the RMI (in Horwich) in the afternoon. It keeps me going; it's the dancing and singing. I go to Llandudno in Wales to the Blind Veterans UK; they are good to me.

My wife enjoys coming here and it's here we find out a lot about what's going on.

I've been coming here a long time; with my husband firstly and then again now. I know everyone here.

I stumbled across 'Social Services' who did the day care sorting out. I got £300 from them although I'm not sure why or where that came from.

We've seen the memory assessment service for several months; Dad's now discharged but we have a number to contact them. The GP's been brilliant and I ensure he has appointments to deal with all the other health issues.

After his hip replacement an Occupational Therapist provided aides; it's been a very good service. Most items have gone now but he still

has the shower stool yet.

After a broken hip she (my wife) has come home from hospital. 'Safehands' (Care Agency) now come daily for 35-40 minutes for washing etc.

We have the aids we need via Bolton Occupational Therapy. We haven't been referred to Bolton Memory Service; our daughter is an ex-carer and so would be able to say if the care is suitable.

A hearing aid has been supplied. My wife sees the GP and the nurse for her anaemia etc.

We are happy with the services we have accessed; if we need anything else we would ask.

People need support on a regular basis either at home or somewhere like this (Dementia Café)

A & E staff are dreadful. Not all but they need dementia training. They don't know how to speak to them. A person doesn't need to go to A & E all the time. The care home have to call them if she has a fall, goes a bit vague (if you put your hand in front of her eyes and she doesn't blink) if she not responsive etc. They have to call however they know that in a few minutes she will be right as rain. A cup of sweat tea and she will be back to normal. But they aren't allowed to do nothing. They would be better if they could call family and explain what's happened and ask if they would like an ambulance calling or not and I would be happy to sign something to say I have said yes or no at that time. That would be better to me. Not only would it prevent precious resources from being used when they shouldn't be, it would reduce the stress for the person with dementia. They can't do anything in hospital. They can't do anything and she gets more stressed. She cries and doesn't know she is in a home. It's always the same they come and try to speak to her. I try and say quietly 'she has dementia' they nod but then just carry on as normal asking her questions that either she can't answer or gets mad about. They ask her things like how old is she and she will say 20. They ask when she last ate and she will either say 'never no one feeds me' or she will say 10minutes ago. They ask about the types of things she does for herself and she will say she still goes shopping daily etc. Of course she doesn't. I try to tell them this but they ignore me. I know they have to speak to her but surely for people with these types of illnesses they should have a different approach. Last time we went they wanted to take her blood. It took so long for them to do this, she was so distressed, and she ended up slipping and hurt her hip. She was black and blue and in so much pain. Eventually they say there is nothing they can do and say she can go home. I can't drive her home as it's too dangerous so we have to wait for an ambulance. When the ambulance comes it can take hours to get her to get in. She doesn't understand why. Then when arriving back at the home she sees the sign and becomes even more distressed. She doesn't believe she lives in a care home. Why can't there be a dedicated person who comes to the home to assess on these occasions. It would be so good if a GP or DR was assigned to a number of homes. When something like this happens (its usually a mini stroke) they could come to the home to do a quick assessment, the family called and they say whether or not they want the person being taken to the hospital. It was save of resources but also help the person themselves. Every time she goes to the hospital she deteriorates further. A person with dementia can't be cured so why make it more difficult.

There is no sense of anyone caring for her. The Occupational Therapist tried repeatedly to get in but my friend refused her help; since then the service has written to the family offering contact if they wanted any more help.

Her family became concerned about her and rang the GP to chat about what they had noticed about my friend. The GP then rang my friend to check out what the family had told them. The family have 'Power of Attorney' and its all over my friends notes. The GP was definitely checking what had been said by the family was correct. It caused my friend to be distressed and again to reject help from the medical profession.

One time we took my friend to A&E with an acute eye problem. We waited 4 hours and after 4 hours of agitation we left and took her home untreated. We were triaged immediately and I assumed that during the waiting time and optical person would be sent for but when I went to ask what was happening I was told that we were waiting for the next free nurse to see her. At that point if an optic involvement was needed then one would be sent for. We had become concerned about my friend as she was obviously becoming distressed at waiting so long and she became very concerned herself about a little old lady who was similarly waiting to be seen. It was quite worrying as, as a nurse, I hadn't taken the decision lightly to take her to A&E.

She has just resumed treatment at the dentist after a 3 year gap as she has complained of toothache. The dentist is private and has

made charges for her missed appointments. We're not sure but we think the Memory Clinic would know where there was a dementia friendly dentist but as my friend isn't a patient of theirs there's no way of finding that out.

Actually because he's now [70s] we've had a letter from our GP saying that his care has been transferred to a [different Dr]. We don't understand why or what that means but wouldn't you think they'd call him for an appointment to review him given his diagnosis and explain what having this new GP means?

What I myself am finding difficult is that my husband's needs aren't the only thing I'm having to manage and cope with. I have a daughter who has anxiety and is currently quite unwell and her husband has his own problems; sometimes I feel I need someone to talk to about how I'm feeling. I know about '1 point' so perhaps I'll give them a ring. As I'm needing to spend more time with my husband I'm finding I don't do the things I enjoy as readily. I'm finding him to be more short tempered and I could do with understanding how I deal with some of his behaviour. It's just dealing with the changes which is making me feel run-down.

I think it would help if there were more services in Westhoughton. Although I drive and I would take him anywhere he wanted to go it would be good if there was a Dementia café in Westhoughton.

Direct payments don't take into account the need to pay for double time on some shifts; we're coming up to that time of year when we'll be faced with that or cover the shifts ourselves but we have lives that involve one of us living with a life limiting illness, employment and the care of other family members. When it snowed last her trip to the day centre was cancelled. The day centre organisers tried her supported housing phone and our family landline number; not being able to reach anyone they left a message. As this was a last minute decision we weren't in to receive the news and so Mum was left with no lunch after her breakfast and as she is diabetic we see this as a 'Safeguarding' situation. The day centre should have made sure they raised one of us so we could plan lunch arrangements. Keeping her safe is our biggest worry. Mum is diabetic and needs insulin twice a day. Although the District Nurses have asked my wife to do the injection and they would train her we don't want what we feel to be a big responsibility as one of us has significant health issues and the other one of us has multi-caring responsibilities already. District Nurses seem to have a slot and they can't be flexible; Mum is up at 6.30 and often needs to be collected at 8.15. but they have had to go to the day centre to find her as she cannot miss her transport. The service on other occasions doesn't seem to be flexible enough to allow her to do certain things that she enjoys. For instance she likes to go to circle dancing but because of traffic issues we are frightened that she wouldn't be home for her 4pm District Nurse slot to have her insulin so we don't take her anymore. It was difficult over

Christmas with family arrangements and there was no flexibility in the system to request a change to allow her to enjoy the family arrangements other than around her time slot with the District Nurse. I think that's why some people end up in care. I know the service is stretched but to at least attempt some flexibility would have a marked effect on my mum's life.

'Meals on Wheels' we found not to be great – the food wasn't up to scratch and the timing of the visits wasn't reliable; sometimes they would come late.

He kept being taken into hospital when the family would have preferred him at home. Whilst he was in we had to keep reminding them about his antibiotics. We would have liked NHS care to be given at home rather than upset him again by taking him out of his environment. We didn't feel he was given adequate pain relief in hospital and we had to ask nursing staff for that to be given to him. We found tablets lying around on the ward and there was blood everywhere.

He went into Darley Court once where the nurse left him in dirty pyjamas which were then given to me to bring home. As doctor told me that there were few staff on at weekend so to bring plenty of visitors to make sure someone was with him.

We weren't told when he descended into dementia only when an allegation of abuse was made. He was finally admitted to 'J' ward where he wandered home more than once in his pyjamas.

When he was in hospital we told the staff we wanted to bring him home but they said he was too ill to come home but we managed to get him home with a care package where carers were to come x4 a day. His care seemed to depend on which carers he got – when they were good they were really good but I gradually became suspicious of them. He had diabetes and the carers didn't seem to know how his illness impacted on the food he could have. They sometimes

didn't turn up; they stole items and cash. They would be leaving at 11 and the next visit would come at 12. I had trusted them. At the end of his life Bolton Hospice were really good and visited him at home; Macmillan services were good and administered the Liverpool Pathway drugs. It was the cruellest death ever but everyone got the chance to say goodbye without restricted visiting. It was better at home, more civilised. For my grandad it was the best thing to be at home. We had to fight for his wishes to be carried out (regarding his death). We were told that's why he had lived so long; he was around his family and in his home; he was content where he was and didn't have to face a lot of change.

Mum had a period where she was experiencing confusion and not sleeping too well. We felt she was a little unsettled and upset about her memory. My brother and I do a lot for her and both of us felt we needed help. We went to the doctor who referred her to the Community Mental Health team. A lady came out; she was here an hour; interestingly the general view was that we were coping. She gave us another list of organisations who could offer help. What we wanted was some practical help; we needed more than a set of leaflets. I didn't know quite what we wanted but it was something practical to help. Mum has been to 'Singing for the Brain' here in Bolton for two or three sessions. My sister has taken her and my brother has too; when I took her I didn't realise that I couldn't leave her but they told me I had to stay because of insurance purposes. I work full time so somewhere that I could take Mum, and pick her up, but leave her so I can continue working, would be really helpful. There is somewhere in Manchester where you can leave your loved one and collect them later after their session but I can't manage to take her so far whilst I'm working. In October 2016 we approached Age UK about the 'Befriending Service' that they run. No one came so I followed it up. They said they would be in touch and in the meantime here's a list of services you can access; another list of services! I chased it up earlier this year again and had a conversation. I wonder if its volunteer time that they are short of which in the world of 'Social Prescribing' is crucial and someone needs to bear this in mind. There's a need for a transport service with an escort or chaperone that can collect someone from their home and drop them off where they need to get to making sure that they have everything they need and all is secure. People need bringing home and escorting into their home too to make sure they are all locked up and feel secure again. Transport is crucial to help individuals get out and have contact with people. The Dementia Specialist Nurse at the Royal Bolton Hospital runs sessions for individuals living with Dementia and their carers around relevant issues. Some of it was really good but I found it wasn't the right place for a carer to off load as it might be in front of the cared for person. Another space would be useful as would a different time which can be difficult for people who work. The timing of the sessions wasn't good either - getting across town for a 6pm start and its tea time! Again the Dementia Café's run in the afternoon and if your family is working they can't take you.

- My husband was recently in hospital for 15 nights; he had no shower and his hair wasn't washed – I don't know why.
 - I rang the District Nurses today; they last came in July and I was told they would come once a month. Its November now and they've not been so I've rung them this morning.
 - Continence pads are provided now. We've had a struggle to find the right ones. Initially we were told there was nothing else and I had to involve the MP to get something more dignified for him.
 - We were told we didn't qualify for a wheelchair and that it's very hard to get a wheelchair so we've provided our own battery one
 - Our gas and electric bills are significant
- The carers we have now are good but I had to report a carer to our Social Worker as they were putting their own shopping in his basket when he went out and did his shopping. She asked my husband for £5 for petrol. I found out she was having her friends in our house whilst I was out. I noticed she was making herself food when she made my husband something. I realised she was even taking chocolate out of the fridge for herself.

There needs to be more information about the 'Blue Badge' Scheme and a separate way of doing it for clients with dementia. How can they answer any questions? Getting blister packs for my Father has been problematic both in terms of getting Dad to know what to do and getting a pharmacist with the resources to do it and the GP to

use that link. It's almost as if we need to introduce things in advance of the individual actually needing them but whilst they have the skills that they need to be able to learn how. Introducing a new thing whether that be an aid or a routine is better to do before a crisis. Getting equipment to be collected has been a challenge. It needs one phone number or plastic bags that you can wrap equipment up in and then deliver to a point where equipment can be collected. Re-ablement staff thought dad was being difficult; it took them a week to work out that although physically he could work the microwave he cognitively had declined to the point where he needed a prompt to heat things up. He wasn't being difficult but had lost that ability to work the microwave.

Grandma said she felt lonely and was expressing that she felt things were getting difficult; she resisted at first but 'Elder Care' came 4 times a day. It was the falls that brought her to the point of not wanting to go home.

There is a need for the carer to be taught about how to speak to the individual with Dementia, what to expect and how to manage situations that arise. I feel my father-in-law has a lot to cope with. They've slipped under the radar because nothing major has happened and because of that I feel she has been missed. He's [70s] and it's a lot for him to manage. There is a need for a more immediate contact point.

My husband's brother, my mother-in-law's other son, initiated contact with the social worker but I do feel there should be a structured follow-up because it's an illness that we and the professionals expect to get worse.

It's the carers in our case; my sister who's her main carer says that she feels like banging her head against a wall.

Her GP has said about her going in a home but we feel she's not physically ill.

The Social Worker used to come on a regular basis but now they don't. They can advise you what's on offer. If mum deteriorated I wouldn't know what to do. There's no ongoing service for mum; it's left to her family.

My brother and I had to insist on communication with ward staff whilst she was in hospital as the nursing staff assumed that mum's partner was capable and able to pass on information. Her partner didn't think like that; quite often he wouldn't tell us things that were happening so we weren't aware fully of what was going on. I feel he

wasn't cut out to deal with what was asked of him. He was upset one day and called her GP who said he wouldn't come out but would discuss her medication over the phone.

Once we'd got her diagnosis there was nothing else; there wasn't enough information about what was going to happen or things that she was entitled to.

Carers from the initial care agency were stopped and after that it seemed a range of different people came to see to her. They often came at 8pm to put her to bed and then didn't come till 9am so she was often in discomfort. Now when I visit her I check if she's in pain and I make sure she gets it. She can have as much as she wants or needs but she won't ask for it. She doesn't want to put people out.

After being in Intermediate Care my mother-in-law is going to go home. She's lost 5 stone and there is a cooker; how can she go home? Carers were going in 3 times a day and we still found rotting food in the fridge including liquefied mushrooms and chicken. Her notes repeatedly said "XXXX didn't want her dinner". She is weak now and I wonder how on earth they are going to send her home. It is alright to give her a bed rail and a toilet but she's not strong enough to use them.

When she was admitted to the Royal Bolton Hospital on E4 to have her arm operated on they let her sign her own consent form. She has a diagnosis of Dementia; I'm not happy with her signing for her operation.

If the person won't go – the help is there but if you are working or the person refuses to go you can't force them.

At the beginning her GP was the barrier. If she could say the answer to the questions it was not possible to refer her. We couldn't get beyond those questions. It's been very hard. If the family are saying there are problems then the GP should refer. For example Nan could remember the address used on the test but couldn't remember where she lived.

Social Services found the first care home although I don't think they realised how bad she was. Her medication wasn't sent with her from hospital which didn't help.

She has her own teeth and they are disgusting. The home needs more support in looking after her dental care. We are noticing a general deterioration.

We had to ask for things.

Her condition was explained to us but we weren't told how to deal with the illness as it showed itself or what to expect.

Continuity of care is important; we liked her to have the same person to get her ready for bed although we would go down. It was difficult for the care company to send the same person and it was different people coming which distressed Mother.

They visited at 5pm and then again at 7.45pm to try to settle Mum. We didn't want to cancel in case we couldn't make it.

Its services where you can leave the person you care for which is

missing; it's so difficult having them with you all the time.

Technological solutions are expensive; Dad doesn't know how to use his mobile phone so technology wouldn't help him.

My wife has some additional needs which affect her bowel and it can be embarrassing for her and for me too. The doctors have said there are 3 options but because of her age one of them is risky and the other 2 don't help her or me to manage. It's like some disabled toilets you have to ask for a key before you can use them; I have to go in with her and it's embarrassing.

As far as the Memory Service goes we've now been discharged back to the care of the GP – hence the Integrated Neighbourhood Team I think.

There needs to be a consistent approach to podiatry; some of us are able to get the NHS service but others of us have to pay!

I saw my GP last week; I was desperate; I couldn't take any more; I'm a carer. I care for my husband. When I saw the GP he prescribed the medication that he (husband) had had before. I don't think my GP knew what to do. My husband has been stressed out so they've given him some medication to deal with his anxiety. Without coming here and chatting to other people we'd have nothing.

There needs to be more services for men around sport for instance. We hear things through 'information holder name) from the 'Staying Well' service which is at our GPs; she's very good. A lot of what we find out is just word of mouth – information feels very splintered.

I am a patient at Harwood Medical Centre – you routinely wait 3 weeks for a routine appointment if it's not an emergency. I feel that is too long to wait in our circumstances. I need to be well to care for my husband.

Ideally we would like a referral back to the Memory Service; he was last seen March 17. He was just discharged back to the care of his GP after his medication was sorted. It needs an easier way to get back into the Memory Service if you've got more symptoms or are worried.

Information is like "too many branches on the tree" and too many numbers to have to work through to find the right person to speak to get help.

When he had a hip replacement it was very difficult as the ward kept ringing for me to come and sort him out even if it was in the middle of the night.

Another time A&E dealt with him after he had had a stroke again and didn't handle him very well. He was left on his own in the waiting room.

We've had no contact with any voluntary services.

1. I have a skin condition which needs me to apply regular cream; I had skin cancer two years ago. I can't get to use the cream so there's no point in keeping my Outpatient appointments. I rang my Consultant's secretary to explain but she told me that unless I keep

the next one I'll have to go back on the waiting list. Its because of my husband; I just don't get the opportunity to use it as I'm caring for him.

2. I've seen services decline since 2008 when my husband was first diagnosed. Why is it it sounds good but in practice these things just don't happen. My husband has had Respite Care in Wilfred Gere; the food portions are so small and there's no fruit. I send him in with fruit. When I asked about that I was told that there is orange juice for breakfast but that residents have to ask for it. My husband can't ask for things – he has dementia.

3. Our Social Worker closed our case and left it for 12 months. When I rang again after the 12 months our money came through – why leave it 12 months when you have a long term problem that's only

going to get more difficult

Care for my mum has ended in that I didn't need to do any of the physical stuff anymore but I still go to see her every week. When I go I take her things she may need. It's not always great as her things often go missing. I buy her new slippers, underwear and clothes almost weekly. I even sew her name in the back of them but they still rarely come back. The home always says it's difficult as they wash so much stuff. I understand however I still don't think it is ok that her belongings aren't returned to her. Sometimes I see someone else wearing something and I think 'I'm sure I bought that for mum the other week' It's not cheap! It still extremely difficult emotionally. Obviously it's my mum and its devastating to see her the way she is. She isn't the mum I knew and loved. Of course I still love her but it's not easy. Sometimes I think she would be better in a different world where she would no longer experience pain. It's a tough one as I love her and don't want her to go but at the same time it's not really a life it's more of an existence. The homes should be more dementia friendly. Why don't they have homes that are set back in the 50's for example. Make the residents feel more at home. They don't want to be sat in a room in a circle watching Jeremy Kyle (that's usually what they are doing) instead make it more like the era in which they believe they are still living.

In sheltered accommodation the scheme manager says family bring them there thinking it's a care home with all the support in residential care.

We had no idea about how to come to terms with the changes when he died. Each person's situation depends on the set up of the family and how the illness affects the patient.

It was difficult for dad to deal with what was happening to his Mother. We say my Grandma turned into something that she wasn't.

Mum now gets Continuing Healthcare. A major thing for us has been communication. Now it's ok but it could have been better earlier.

After mum died we realised we had taken her to the hairdressers and I had visited every Tues and every Monday after work and sometimes at night when we got a call. We also covered every evening if the carer was on holiday.

Dad feels better now he knows she's in a safe place although when we visit we feel sad.

I find that I can't go anywhere where I've been previously with my husband. We used to dance but I don't want to dance with anyone else. I'm lonely; I'd like someone to go out with. I come here because I brought my husband who has now died.

I am seeing more of my cousin now, as long as he stays well; he's in the same position as me.

I still come here for the support and friendship. My husband died 7 years ago.

I still come here; my wife died and she ended up in Mill View Care Home. She went to Firwood and one day they said I couldn't carry on looking after her. She had got that she didn't always recognise me; it was terrible. She hit her own son; he was [50s] and he cried.

There are many things and most relate to how things could be improved, for example:

A forum for families where families can meet and talk to others would be fantastic. I would love to have gone to something like that 8yrs ago when my mum was first ill. I just wish there was somewhere to go. She looks in the mirror and sees an old lady but doesn't look at herself as an old lady. At one point she told us that she was being raped. She thought someone was coming into her room at night. Understandably we were devastated. The whole family were distressed and didn't know what to do. There was a whole investigation and it ended up being that she was seeing her reflection in the mirror but didn't see it as herself so thought someone was coming into her room. We ended up having the mirror removed. It caused huge difficulties for everyone. The family argued and fell out as we were all under strain about what to do. Call the memory clinic something different as they remember names and what they do so refuse to go.

Could a member of the family go to the memory clinic instead if the person themselves won't go? Like I said my mum wouldn't go meaning we got no diagnosis and as such no support. If we had been told we could go as family members and speak to someone and get some leaflets at least this would have helped. Age UK were great but very understaffed, lots of it was leaflets 'take away and read yourself.' Sometimes you need to speak to someone and ask

questions. It's such a confusing time.

If we didn't do the 1 day a week caring for my friend it would be more for someone else; we try to spread it around. We are concerned for the person who is most close to her and spends most time with her. It's a significant impact on their life and we can see how much that is affecting them.

We worry about her safety at home; we worry about the iron and the cooker.

We have asked Social Services for her to be able to go into residential care but it's been refused by Bolton Council. We believe she's deteriorating and I was struggling to cope with everything. We are asking to use the Direct Payment for Respite Care; that request was made in April 2017 – here we are in December and still waiting for something to happen. All the Social Services assessments only assess the client's needs and they won't assess her needs alongside my other caring responsibilities. We feel the current assessment only allows someone the same level of care irrespective of that families other responsibilities. At times I've been caring for 6 people; the issues around individuals who are 'Multi-carers' need looking at.

Mum has her podiatry whilst she's at Winnifred Kettle – it's a private service but its easier for us than trying to fit in the NHS service and have to take her to wherever it would be.

The Continance Service wanted an 'input' and 'output' record for her which would have been difficult to do and their aids were unsuitable and undignified anyway so we provide Mum's needs now.

Ideas for what would help:-

- For people newly diagnosed it's someone to walk with the family on an individual basis encouraging people to think about how life is going to pan out; group work isn't for everyone.

- Someone who could network among the Dementia Community
- An 'early on-set' Alzheimer's service

We had no idea about the cost of a funeral; its almost as it you need a 'Care Plan' for death. There are bereavement teams at the hospital and at the hospice which could help with information.

I'm not well; I have COPD and asthma. I keep trying to get out as I get bad headaches. No one comes into help when I'm unwell; I still carry on. Before I can go away I've to sort everything out before I can leave him with family. He doesn't like Respite Care; when the house was being got ready he had a bad experience of Respite Care. As an ex-veteran he goes to their home at Southport.

People don't know that the cost of Care line is only about £1 a week more to have a warden respond as the first on-call.

Finances have been a big thing; we've got Power of Attorney, dad's now allowed that power. Grandma goes to the meetings about her finances because its her affairs but she doesn't fully understand since her diagnosis. We feel there is inequality in the financial implications; if you own your home you have to pay whereas if you don't you get the care anyway.

My mother-in-law's sons can't seem to do a lot due to their dad not letting them. I don't think dad wants to give in. He sees it that it's as if he can't cope. Two years before my mother-in-law's diagnosis we had to deal with her mother's death from the same illness. In our experience in dealing with both these illnesses is that people don't understand the illness. Even my father-in-law gets cross with my mother-in-law when he has to keep repeating things.

I work full time and then go to my mums on a Sunday and sleep over. My sister and brother bear the bigger load; it falls mainly on them. I feel sorry for them. All her children work full time and have their own homes to care for. It's wrong that people have to pay and lose their homes; they've worked hard for them and my dad too. I grew up there. Carers Allowance is ridiculous; you can't manage on that. I worry for myself; I don't want to rely on my family for feeding and washing. It's not right that her own son is having to wash and change her.

The support was mainly for my grandma but not much for us as her family; we felt there was a need for information and support. A support group would have been useful.

Currently her fees are paid with Continuing Healthcare payments. Mum and dad pay some top-up fees which my family don't object to. She had lots of friends at the start but as she couldn't speak they

were embarrassed. Mum was well known in her neighbourhood and had been for 50 years. There's a need for community support through a befriending organisation; we were told there was a waiting list for a luncheon club.

The Memory Service has been good; we have another 2 visits over the next two months. If I'm worried I can ring. It feels like everything we get we have to push ourselves forward for. It seems that you find out things almost by accident or a chance conversation.

People need more trips out; trips to the seaside for instance. Dad needs other men's company through things like family trips. We need more help with financial matters; they could be done through a drop in session. What happens to his house if he goes into a home?

An idea if there is any extra funding around would be for help with transport; people in dad's circumstances lose their driving licence and so find they can't get out as easily. A lot of people in Dad's circumstances won't go out at night.

It's getting about now. I use 'Dial-a-ride' a lot as I can't walk far now. Taxis are expensive. My neighbour is very good to me and takes me shopping once a week.

If there was any money about we think it was best to have a follow up after 6 months and 6 monthly assessments which are more than just blood pressure and 'waterwork' checks which is what happens now at the GP's. It was 18 months ago that he was last seen; its advice about what to do next that would be useful to us.

Showering was an issue. Myself and my sister have to make him have a shower and change into his pyjamas.

We know how to ask but don't feel lacking in anything.