

Living with Dementia in Wakefield District: Discharged at Diagnosis?

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Executive Summary

Dementia is an umbrella term for a range of progressive conditions affecting the brain. Although the condition is more commonly diagnosed in people aged 65 and over, it can affect people at any age. In Wakefield District, it is estimated that over 4,000 people live with dementia and in line with the forecasted numbers for England, this is set to rise to over 4,800 by 2020.

Dementia has a huge impact on people's lives, the different types of this condition presenting different issues for the affected person, their carers and their family. Although many people with dementia maintain their independence and can live well for years post-diagnosis, caring for them, albeit rewarding, is also challenging due to behavioural and personality changes, family dynamics and the negative impact on carers' psychological and physical health, particularly in the later stages when the support provided by carers increases in order to fulfil everyday tasks.

In order to help improve patient and carer experiences of dementia services in our district, Wakefield's New Models of Care Board commissioned Healthwatch Wakefield to gather information relating to when an individual begins to deteriorate beyond their carers' ability to manage.

The aim of the project was to gain a better understanding of how prepared family members or carers feel when dementia begins to result in significant behavioural challenges, as well identifying gaps or good practices where support is concerned. However, carers were keen to explain a wide range of factors that contribute to the challenges they face and these have been included in this report, in order to ensure that their opinions and experiences are shared with policy makers and service providers.

Key findings

- People told us that it takes too long to receive a confirmed dementia diagnosis in Wakefield, sometimes impacted by GPs not offering or recommending follow-up appointments to re-test people who suspect something is wrong.
- Medicalisation (particularly at the initial stages of dementia) was viewed favourably by many people we spoke to, who value the diagnosis, information and support provided by dementia specialists.
- Many of the people we spoke to felt that dementia is not viewed to be as important as other terminal diseases by health services in the District.
- Variations exist when it came to the amount of information people receive about dementia and corresponding support. Some people were overwhelmed and others felt that information should be more bespoke, but there also seemed to be a lot of overlap in information provided by different organisations. Information shared at carer groups and courses held by charities and health professionals are invaluable.
- Respite care doesn't meet people's varying needs; there are barriers to overcome such as time, planning, or staff resources and it is difficult to access. Lack of continuity with regards to staff has a negative impact on the person living with dementia.

- Carers are negatively impacted by the cost of caring, which can have a detrimental knock on effect on their health and wellbeing. Some carers disregard their own health in fear of neglecting the care of the person living with dementia. As the dementia develops, it is more challenging for carers to meet basic needs; the domino effect on carer health and wellbeing can also escalate as a result.
- Although there are many types of support groups available, these are still difficult for some carers to access due to factors relating to cost, accessibility to respite care, transport and time pressures.
- Compassionate health professionals and support services are valued by people in receipt of it. However, not everyone experiences it.
- Accessing help was a massive issue highlighted by almost everyone Healthwatch Wakefield interviewed, who on the whole felt that their needs weren't being met.
- People don't seem to understand how social care works for people living with dementia in the District and find accessing social services difficult. They also don't feel that social services always have a good understanding of dementia (or the different kinds of dementia).
- The lack of continuity from professional caregivers is confusing, can lead to negative behaviours and hampers the transferral of useful information between the carer and the care or healthcare provider.
- As needs become more complex or the condition of the person living with dementia deteriorates, some carers have found their loved ones experiencing unsuitable and detrimental help, particularly between care homes and Pinderfields General Hospital.
- Admiral Nurses are a much valued source of help and carers would like to see more (or more specialist help in general) in Wakefield District to help meet demand.
- Some service users currently perceive health services and other organisations helping people living with dementia as being in competition with one another, rather than working together for the benefit of those who need their help.
- There are mixed opinions on advanced care planning (ACP) by both carers and healthcare professionals. Generally ACP is seen as a positive thing to do, but people question if people with other terminal diseases are encouraged to do this and the appropriateness of ACP, as the condition of the person living with dementia changes.

“I got my support from the general public, not the medical side. To say it's a medical condition, they walk you out the door and say goodbye.”

Recommendations

1. In order to avoid potential delays to a dementia diagnosis:
 - a. GPs should offer or recommend follow-up appointments to people who suspect dementia, but have passed the initial cognitive tests; and / or
 - b. People who suspect dementia or have behavioural changes/issues with memory should be referred to GPs with more specialist dementia knowledge.
2. The length of time between seeing the GP and having an assessment at the Memory Clinic needs to be shortened to not only speed up diagnosis, possible treatment and support, but to allay the impression that dementia is not as important as other terminal illnesses.
3. GPs should not be charging for the production of medical reports if this is required to help families access financial support during times of hardship.
4. Access to specialist consultants and dementia nurse consultants is much valued; increase regular contact between specialist health professionals, patients and their carers, which could lead to increased preparedness and a reduction in crisis incidents.
5. Services need to review some of the terminology used and services on offer for people living with early onset dementia, whose carers do not always feel that they or their loved ones are catered for appropriately (e.g. the Memory Clinic is classified as an Elderly Persons' Service). Due to this carers can feel a reluctance to access such services as they don't feel that their loved ones belong there.
6. Services need to also acknowledge that carers of older people living with early onset dementia have different challenges that do not apply to older people, such as not being retired and having to work.
7. When providing people with information:
 - a. Take time/offer to go through information with patients and relatives and then contact them (or get a charity to contact them) some days later to revisit information. This might be a good time to also start tackling more practical tasks.
 - b. Encourage people to involve close family members/friends when it comes to reading information and tackling tasks, to help overcome feeling overwhelmed and to be more prepared.
 - c. Avoid medical terminology, particularly in the beginning stages as this can be unfamiliar language. However, written reports need to be detailed enough so that people can refer to this at later stages in order to feel better informed.
 - d. Ensure contact details on leaflets are up to date and the correct department will respond to queries and effectively guide people as a result of them using that source of information.
 - e. Avoid duplicating information, organisations helping people living with dementia and their carers should work more collaboratively by sharing/promoting one another's resources.
 - f. Make it more bespoke, particularly for carers of people with early onset dementia, who do not feel dementia services are relatable to their circumstances or age group.
 - g. Split it into stages to help people tackle changes or new circumstances, e.g. tackling dental health, preparing for travel.
8. More support needs to be provided to help children and young people with parents/close loved ones living with dementia, to help them better understand the condition, but to also help them to tackle the impact of change in their lives.

9. Help carers with their financial burden:
 - a. A local carers' passport scheme that potentially aligns with the Safer Places Wakefield scheme could help carers to both identify dementia friendly venues and services, but also receive offers or discounts, which could incentivise them to go out more often as well as with more confidence.
 - b. Information regarding financial support should be readily accessible and efficiently shared with carers, who should be informed of any recent changes in policy.
10. Listen to the carers' needs and their innovative suggestions (such as a co-operative respite care system) in order to provide a wider variety (and more) affordable respite care, which is also responsive and relevant to the changing needs of the person living with dementia.
11. Promote health and wellbeing:
 - a. Encourage a proactive response to dementia diagnoses by encouraging the mental and physical stimulation of the person living with dementia.
 - b. Carers need to feel able to express a decline in their own mental or physical health and not be reluctant to take care of themselves or take medication in fear of this affecting their ability to care.
 - c. GPs need to take the time to explain the impact of medication for a carer, but also initiate access to help where necessary so that a carer doesn't neglect their own health.
 - d. Providing training around mental resilience may help carers to better cope.
 - e. Policies that mean that the basic health needs of a person living with dementia, such as limitations on continence pads, should be revised with immediate effect.
12. Peer support groups need to be spread across Wakefield District and in easily accessible venues that take into consideration factors such as bus routes and pressures on carers' time.
13. Health and social care professionals should be reminded about the importance of compassion, but also given the opportunity to receive awareness raising on compassion.
14. With the rising age of the general population and forecasted rising numbers of people living in dementia, mandatory dementia training should be provided to those health and social care professionals who are more likely to interact with people living with dementia and their carers.
15. Social care services need to be more proactive around how they can help people living with dementia. The service needs to be more responsive to enquiries and answer people's questions in a timely manner.
16. Ensure Continuity of staff, be it GPs or professional care providers, as a vital way in which to reduce levels of confusion or negative behaviours in the person living with dementia.
17. Develop an improved care pathway to avoid the damaging relay of people living with dementia being passed back and forth between care homes and Pinderfields General Hospital.
18. Improve the access to specialist dementia health (and social) care professionals, e.g. increase the number of dementia/Admiral Nurses in Wakefield.

19. Improve communication between departments and organisations and encourage working together in order to effectively help people living with dementia.
20. If advanced care planning is agreed, this must be reviewed to meet the changing needs of the person living with dementia and their carer.

“...the whole experience was not emotionally comforting... It’s hard to explain, PLWD had cancer a few years ago and there was much more wraparound, where the emotional wraparound isn't here. With this, there's no future and we know something nasty will eventually happen.”

Introduction

Dementia is an umbrella term for a range of progressive conditions affecting the brain, the most common being Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia¹. Although the condition is more commonly diagnosed in people aged 65 and over, it can affect people at any age¹. It is estimated that 676,000 people currently live with dementia in England and this number is set to rise with the increasing ageing population². In Wakefield District, it is estimated that over 4,000 people live with dementia and in line with the forecasted numbers for England, this is set to rise to over 4,800 by 2020³.

Dementia has a huge impact on people's lives, the different types of this condition presenting different issues for the affected person, their carers and their family⁴. Although many people with dementia maintain their independence and can live well for years post diagnosis⁵, caring for them albeit rewarding, is also challenging due to behavioural and personality changes, family dynamics and the negative impact on carers' psychological and physical health⁶, particularly in the later stages when the support provided by carers increases in order to fulfil everyday tasks⁵.

In England, there are around 540,000 carers of people with dementia³, 63% of whom are retired, 18% are in paid work, while another 15% are not in work because of their caring responsibilities². The current cost of dementia in the UK is £26bn² and much of this shouldered by the people affected^{2,7}.

Purpose of the Evaluation and Objectives

In order to help improve patient and carer experiences of dementia services in our district, Wakefield's New Models of Care Board commissioned Healthwatch Wakefield to gather information relating to when an individual begins to deteriorate beyond their carers' ability to manage. This is important because poor management of the later stages of dementia result in very poor experiences for both the person living with dementia and their carer, in addition to expensive and sometimes sub-optimal system responses.

The aim of the project was to gain a better understanding of how prepared family members or carers feel when dementia begins to result in significant behavioural challenges, as well identifying gaps or good practices where support is concerned.

Evaluation Methods

The project consisted of two stages; the first being informal semi-structured qualitative interviews, where the researcher would gather the experiences of carers and that of the person living with dementia (where possible) face-to-face. These interviews were primarily conducted in carers' homes – this being the easiest place for in-depth conversations to take place with minimal disruption and additionally, more comfortable for the person living with dementia.

¹ Dementia UK: <https://www.dementiauk.org/understanding-dementia/advice-and-information/dementia-first-steps/what-is-dementia/>

² Dementia Statistics Hub: <https://www.dementiastatistics.org/statistics/prevalence-by-age-in-the-uk/>

³ Wakefield Council: <https://www.wakefield.gov.uk/Documents/health-care-advice/adult-services/dementia-friendly-wakefield.pdf>

⁴ Public Health England (2017): <https://www.england.nhs.uk/wp-content/uploads/2017/07/cfv-wakefield-mhidp.pdf>

⁵ Carers Wakefield: <http://www.carerswakefield.org.uk/support/dementia/>

⁶ Alzheimer's Research UK: <https://www.alzheimersresearchuk.org/wp-content/uploads/2015/12/Dementia-in-the-Family-The-impact-on-carers.pdf>

⁷ Alzheimer's Society: <https://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf>

Healthwatch Wakefield planned to conduct two focus group discussions with carers, but was only able to carry out one session. This was mainly due to issues around timing and carers not feeling confident that they would be able to participate in an in-depth group discussion, whilst simultaneously caring for the person living with dementia in an unfamiliar location, or away from home. We also sought to hold a focus group alongside (or replacing) a regular carers group session. However, having time away from much valued support or interactions with professionals and other carers, or not being able to participate in activities was not something people were keen to give up, as these occasions support the wellbeing of the carer and/or the person living with dementia.

The questions we posed at both the individual interviews and the focus group centred around, but were not limited to:

- Whether the process around diagnosis and support felt too medicalised;
- What information had been provided about dementia and the likely trajectory of the disease;
- What information had been provided regarding support and if this had been followed up;
- If practical information and advice were provided;
- How the person living with dementia and their carer were coping, as well as what their thoughts were if they were unable to cope anymore;
- Whether or not advanced care planning had been done and if it had been helpful;
- What had worked well and not so well.

Healthwatch people spoke to 19 people in total; everyone barring one focus group participant lives in the District and many of the carers were interested in receiving a copy of this report.

We also spoke to some health professionals working with carers and people living with dementia, who provided us with additional insight into their experiences of providing support to people living with dementia and their carers in the district.

Approach

Healthwatch Wakefield's Engagement Officer visited a variety of different venues where carers and people living with dementia participate in activities or attend support groups. The Engagement Officer provided information regarding this project and obtained consent from those people who were interested in being involved in either the one-to-one interviews or focus groups (the vast majority of whom preferred the former option).

The researcher then contacted the individuals who were interested in participating and met with all of those people who responded to phone calls or email messages in their homes, except for one couple who preferred to meet in a café. On the day of each interview, every carer was asked to read an information sheet about this project and another detailing how Healthwatch Wakefield would use their information, followed by a request for them to complete a further consent form agreeing that they were happy to participate and continue with the interview. The same process was carried out for people participating in the focus group.

The researcher asked for some background information in order to initiate the conversation and proceeded to ask a series of questions based on a semi-structured qualitative interview, lasting approximately one to two hours, depending on the amount of information the participant(s) wanted to provide. In total, Healthwatch Wakefield spoke to nine carers on a one-to-one basis, concerning seven people living with dementia (although one carer did also refer to another relative living with the condition, but not lesser detail) and ten carers in the focus group, which lasted two hours.

Findings

The following information has been split into themes and is based on information gathered from one-to-one interviews, the focus group and conversations with health professionals as detailed previously in this report. The people living with dementia referred to in this report have a variety of different types of the condition – not everyone specified the exact type, but Alzheimer’s disease, vascular dementia, frontotemporal dementia, early onset dementia and mixed dementia were mentioned by some of the carers we spoke to.

In order to maintain as much anonymity as possible for the carers and people living with dementia in this report, their names and gender have been replaced with PLWD (Person Living with Dementia] in the quotes contained in this report.

Diagnosis

The route to being diagnosed with dementia

All the people we spoke to in the one-to-one interviews had noticed behavioural or mood changes in their loved ones and subsequently spoke to their GPs about their concerns, which was also echoed in comments made by some people participating in the focus group. However, the route to a confirmed dementia diagnosis varied; two people had a fairly straightforward experience where they were referred to the Memory Clinic and were diagnosed after an assessment and brain scan, two others were diagnosed with depression or anxiety and then diagnosed with dementia at a later stage, and three people were advised to wait or had borderline diagnoses that eventually led to dementia assessments and a diagnosis at a later point (see Diagram 1 on page 12).

It was common amongst the carers we spoke to that they felt something had changed or wasn’t quite right, which led them to booking an appointment with a GP (this was sometimes two to three years prior to a confirmed diagnosis) and didn’t always lead to an assessment by a dementia specialist, e.g. being diagnosed with a mental health problem such as depression or anxiety, or being told that there was nothing to be worried about.

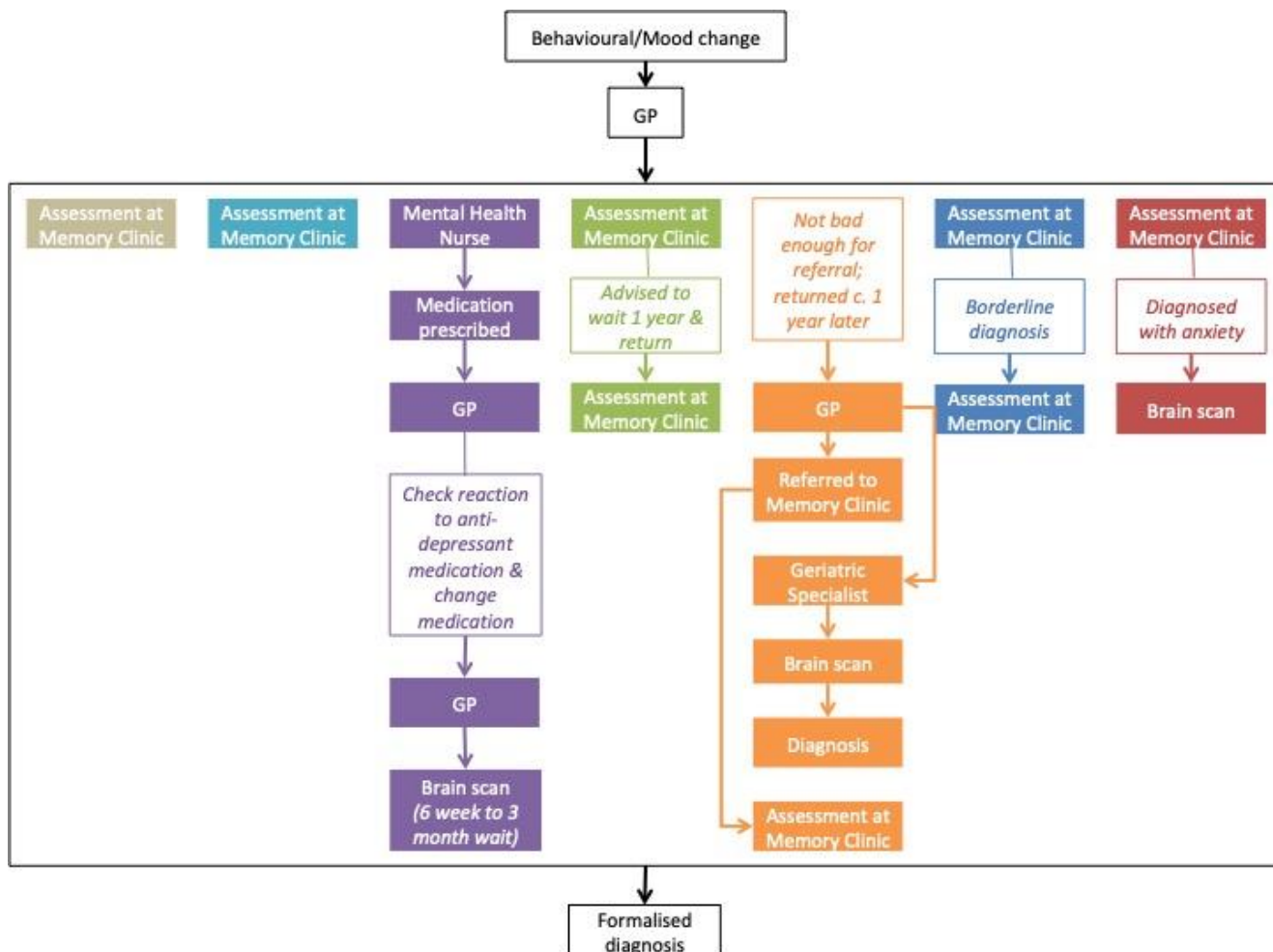
“For over two years PLWD was treated for depression, but I knew it wasn't depression even though the mental health nurse said otherwise. I live with PLWD!”

“I monitored PLWD for a year before, due to what PLWD was saying/doing.”

“I thought PLWD’s personality was changing – we went on holiday as usual but PLWD wasn't doing the kinds of things they always liked to do on holiday, or PLWD would come back home from a usual hobby and complain about it.”

“PLWD was originally diagnosed with depression but I felt it wasn't, as I've had depression and the behaviour was very random... It started with PLWD decorating - usually it was good, but this time it was horrendous and when I said so, PLWD started ranting, when PLWD is usually laid back... PLWD couldn't do some things as before and I thought this isn't right.”

Diagram 1: Route to dementia diagnosis



Once a GP had made the referral to the Memory Clinic in Wakefield, some people still felt that the wait for a confirmed diagnosis was too lengthy, even when taking into consideration what some people had felt was an inaccurate initial diagnosis, which already delayed the process.

“... finally went for a brain scan - the results took between six weeks and three months to come back... it took far too long!”

“There was a big gap between February and July and we were told that it would be a big gap. It would be lovely NOT to have a big gap... like they have for cancer, is it 18 weeks? The protocol for cancer is very clear, they should have no more than one month/two maximum delay.”

We also spoke to the Admiral Nurses who told us how long it can take to get a diagnostic appointment, but who have also experienced a lot of demand from people who are concerned about dementia and not always certain of what they should be doing.

“A diagnostic appointment can take five to six months. A carer told us that he's in limbo as he can't get medication for his loved one. When it comes to vascular dementia, there is no effective treatment, so they get the diagnosis and are then discharged.”

“We had an event in Middlestown Surgery and 24 people came along needing advice and support - all stages, but all the people we saw were appropriate. Some had worries about memory, some had scans, some were diagnosed but didn't know what to do. That was one surgery for two hours... we need to do more surgery sessions as one of you for two hours is not enough.”

Medicalisation

Medicalisation is defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it⁸. Some people told us that they felt the system wasn't medicalised or not medicalised enough.

"The service isn't medicalised enough - you get the result and then they write you off."

"Is the process too medicalised? No."

Medicalisation was particularly positive for one carer, who was frustrated by the length of time it took for their loved one to be seen at the Memory Clinic and was advised by a relative to seek specialist help whilst waiting for an appointment there. They had found the appointment with a Geriatric Specialist to be a very positive experience and extremely helpful. This consultation had also led to a fast diagnosis; the same result being determined several months later by the Memory Clinic.

"We were referred to the Memory Clinic, then made calls to various places like Age UK; the usual places where you would go from here... A relative asked why PLWD wasn't seeing a Geriatric Specialist, as PLWD has complex health needs. I told the GP I wanted to see one and it was the best experience of my life; a very very good consultation and the specialist also chased for a brain scan... Having a Geriatric Specialist should be something that everyone should be given... The poor GPs have to do everything. So we had seen the scan, saw a Geriatrician, then eventually were seen in the Memory Clinic when the diagnosis was made formal five months later."

Dementia training

Some carers implied that there is a need for more dementia training amongst health professionals in order for faster referrals to take place. In addition, communication from the GP to the patient could have been improved upon, as sometimes the length of time between an initial appointment where no referral was made (e.g. due to a person passing the GP's initial dementia test), to a second appointment where the person's condition had worsened considerably, was too long. This may be due to people feeling that they were worrying needlessly as a result of the initial GP appointment, even more so if there isn't an offer or suggestion for a follow-up or review appointment. The impact of a delayed diagnosis also negatively affected one family's financial security, which was further exasperated by their GP asking for payments for the production of medical reports in order for them to access financial support.

"We saw a locum at Fieldhead, who said 'PLWD can't have dementia as PLWD's not old enough'!"

"We went to the GP who told us that it wasn't bad enough for a referral... one year later PLWD said, 'help me, what day is it today'... It continued for a few days, so we went to the GP, who told me off for waiting."

"GPs don't understand dementia. It feels like they've been trained on one type of dementia, but each person should be treated as an individual...!"

"In PLWD's new job, the probationary period was extended as PLWD couldn't seem to fetch things or read, then lost their job... I went with PLWD to see the GP who referred us to the memory clinic, where PLWD was diagnosed as borderline... It was hard as we were told that PLWD was fit for work by the PIP assessment centre, but PLWD couldn't remember our address or the vowels when filling in forms... They stopped our benefits, so PLWD had to look for a new job. It was a vicious circle... We went without benefits for two years and had to borrow money from a relative... We went back to the Memory Clinic and Sociologist where PLWD was diagnosed. Every cognitive skill

⁸ Medicalisation and Overdiagnosis: What Society Does to Medicine: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5088721/>

was affected. PIP would take the report and read it, but said they would have to take PLWD's word for it - so PIP failed us, as the lady wouldn't accept the findings! Thankfully I knew someone who used to do PIP and got her involved - this time the PIP person knew all about Alzheimer's."

"I got annoyed with the GP who was trying to get me to pay for medical reports. You are asking the most vulnerable people to pay. I fought it, but at least now the GPs are supportive."

There is also a need for dementia specialists to avoid using complex medical terminology in order to help people understand the diagnosis. It may also be better for the information provided during the initial diagnosis appointment to be more basic, but backed up by detail in reports, so that carers can refer to this at later points.

"Specialists talk like you're aware of terminology... I didn't know what questions to ask. I only asked how long till PLWD gets very ill – the consultant said 'I don't know'... I can't remember everything the consultant said and the report is too vague."

Post-diagnosis

Feelings of abandonment

Once dementia was confirmed by the Memory Clinic, many people felt that they had been physically and/or emotionally abandoned, due to dementia being a terminal disease. They expressed a desire to be told what to expect next, particularly with regards to what they felt was a de-medicalisation of the service they expected or had once received, and a move into social care. However, people expressed gratitude for the much valued support provided by Admiral Nurses (specialist dementia nurses) and the Alzheimer's Society.

"I haven't really thought about what [the Memory Clinic] could do, so I don't get upset. They're a clinical service... This is the only terminal disease where you're discharged when you are diagnosed... I think that the Memory Clinic are now doing six-monthly reviews, which sounds good... maybe it's a reaction to people feeling abandoned, as they are discharged at illness."

"I feel psychologically abandoned, but I'm also rational and don't worry about it. They move you out of a clinical service and into a social care service and what does that give you? Respite, support, groups, visits... we need more Admiral Nurses... The Memory Service need to explain that people aren't being abandoned, but are moving you to another place or service."

"The Memory Clinic was good. I fully understand why there is nothing they can do. We're blessed with the Alzheimer's Society and Admiral Nurses."

"We settled down in our routine and the Memory Clinic saw PLWD regularly until two years ago when PLWD was discharged - 'sorry we can't do any more'... we saw a consultant, nurse, then PLWD was discharged. Suddenly the GP called and rang to see how we are doing."

"I got my support from the general public, not the medical side. To say it's a medical condition, they walk you out the door and say goodbye."

Comparisons to other terminal diseases

The carers we spoke to often referred to other types of diseases that can be terminal, especially cancer. They felt cancer patients were generally offered more involved and compassionate support and care in comparison to people living with dementia. Some people felt that more money goes towards cancer research or services because there can be a chance for remission, or that the illness can be managed successfully long-term, whereas there is always a decline in cognitive function and a terminal diagnosis with dementia. This sentiment made people feel that dementia isn't being treated fairly, such as splitting it into specific categories to provide more specialised help to better support the person living with dementia.

“The Memory Service isn’t brilliant. The whole experience was not emotionally comforting... It’s hard to explain, PLWD had cancer a few years ago and there was much more wraparound, where the emotional wraparound isn’t here. With this, there’s no future and we know something nasty will eventually happen.”

“Dementia has become what cancer used to be - people are frightened of it. The ratio of cancer research to dementia research... we need more money in the dementia research pot.”

“Alzheimer’s is not a sexy brand - people with Alzheimer’s are old and have to die of something, whereas with cancer, it can be young people with a chance to live or get better. We’ve caught an old person’s disease. It would be better if they could think of another name for Early Onset Dementia, as this is not an old person’s disease. Even the Memory Clinic - it’s part of the Elderly Person’s service - we’re being pigeonholed into something we’re not. We’re a minority, we’re unfortunate in that respect.”

“PLWD has now been passed on to the GP. Since then you don’t feel as if... you get the impression that they don’t really know what to do, or don’t have the knowledge to deal with someone with dementia and Alzheimer’s. You wouldn’t refer a cancer patient back to a GP, or any other illness. They wouldn’t do that to someone with MS or Parkinson’s.”

“Dementia is an illness; we should treat it that way.”

Information

Healthwatch Wakefield also asked people to tell us about the information they had received. We were given a mixed response; some people were provided with no or minimal information, others were happy with the information given to them and others felt overwhelmed to the point where they didn’t feel able to read any more or know what to do first.

“It was ‘yes it’s Alzheimer’s’ and that was it. No information was given to me.”

“The GP did not provide any advice or any information, like about Alzheimer’s UK.”

“The Dementia Nurse came with loads of information. I then started going to the Memory Café and Singing for the Brain even before going to the Memory Clinic and brain scan.”

“Lots of information and leaflets. It was overload!”

The way in which information was provided affected how people felt about the way in which they were treated; if things were explained in a hurried or clinical way, this was the beginning of feeling abandoned for some. People were frustrated when the information provided wasn’t as described in a leaflet they received, e.g. they weren’t speaking to the people who could help them. In direct contrast, other carers had very positive experiences because information led to effective actions due to accessible and professional guidance.

“We were told it was dementia... gave me leaflets, explained what dementia was and that was it!”

“The Memory clinic give you a leaflet, tell you about tablets, tell you how they will be assessed in six months and twelve months... It’s like you’ve got a cold. There’s a phone number at the bottom of leaflet - you phone and you get passed on to someone else.”

“The Memory Clinic gave us the bulk of information via [Nurse Consultant]. We’d call and ask him for advice. We always saw [Nurse Consultant] because PLWD’s condition was so severe. It was great to have that same contact and specialist knowledge. It’s not like that now.”

“I had no idea how to recruit a carer [for another relative]. The Admiral Nurses put me in touch with Penderels Trust, who came to see us and helped me interview potential PAs. I’ve employed a carer who is fantastic - that one bit of information made a huge difference to us.”

Some carers expressed their frustration regarding the amount of overlap of information being provided by different organisations, which meant that there was a lot of repetition in leaflets explaining the same or similar things. This made them feel that pressures on their time wasn’t being recognised (i.e. not having the time to read through everything) and that valuable money or resources were being wasted, or could be better utilised by organisations and charities if they worked more collaboratively. However, one way of tackling the overlapping of information in a practical way has been the creation of an activities calendar by the Admiral Nurses, which includes events that are not led by them.

“I have more pamphlets than I know what to do with – they all say the same thing.”

“The Admiral Nurses have started to do a calendar - activities and not just Admiral Nurse stuff.”

“There’s a whole raft of activities - you could do something every day if you wanted. The Admiral Nurses pull the diary together and pass on information about different activities.”

Improved methods of sharing information

In addition to the feedback provided above, people who felt that they hadn’t been given enough information often stated that what they really wanted was basic, practical information or guidance at the very beginning stages (but also avoid duplication at later stages) to avoid feeling overwhelmed. This would help them to absorb the fact that dementia has been diagnosed and then action what needs to be prioritised, while they adapt.

“Information is what is lacking - support for him and her. Especially in the beginning.”

“We should be given a pack of what to do/what not to do... all the information. It would be so much easier.”

“Help needs to be at the beginning of the diagnosis... what the hell do I do now?! What next?”

“In the beginning you need someone in the medical profession to help you out. A pack by the Alzheimer’s Society or Admiral Nurses.”

“I would have liked the information after it sunk in, so that I could absorb it.”

Relatives of some older carers told us that they should be encouraged to share information with other involved relatives such as adult offspring. Health professionals could also be more proactive by involving relatives in order to better help older carers and the person living with dementia to avoid or minimise difficulties at later stages, but also by following up information to ensure people understand the diagnosis and what they should consider doing first. There was also a desire for information to be more bespoke, or more appropriate for those people who are still working.

“Mum didn’t want to acknowledge [the dementia diagnosis] and didn’t even read the leaflet.”

"I got information the very day PLWD was diagnosed. It was a shock... I don't understand the system, I was working 45 hours and coming home to who knows what. It was too much, too soon and no follow-up. They should do a follow-up in two weeks for it all to sink in."

"The information should be more bespoke – it's irrelevant if you're working. We need more explanation from the specialist... People ask me if its front lobe - I don't know! "

"I went to Alzheimer's UK and Carers - all the things you read assume you're not working. We need more Early Onset dementia info."

Do-it-yourself research and learning

Some people were very proactive and conducted their own research even prior to a confirmed diagnosis if they suspected dementia in their loved ones. They often found it helped them to better understand the condition, prepare themselves and learn about accessing financial help or care services. Some carers were really keen to share what they had learnt, even setting up their own support groups and information packs.

"I got lots of literature/read lots - so it wasn't a great shock and I'd already started adapting things."

"Before the diagnosis, I went to the Alzheimer's Society for information."

"Google was my best friend. I had to research everything myself – it kept me a step ahead."

"... even before PLWD was diagnosed, I went to the Alzheimer's Society and asked them what's out there... I also got a lot of information from people I know... I've already done power of attorney and attendance allowance."

"I did my research. Some people don't fully accept the situation. People aren't learning about it. Memory Action Group are trying to get a practical pack together... The Admiral Nurses are also trying to get a brochure together."

Support groups and courses

Courses and groups where carers and people living with dementia meet have also been a valuable source of information sharing, learning and support, enabling people to complete important actions or access practical forms of help and financial support. However, due to the types of dementia some people have, such as early onset dementia, courses can feel irrelevant or not relatable and access can be difficult for working carers.

"I got the number to Carers Wakefield - best thing I ever did. I go once a month to meetings - helped us with power of attorney, filling out forms (although they're not supposed to), benefits..."

"... chatting amongst one another makes you learn – the best way of learning is together and from one another."

"I went to the Forget-Me-Not café at the beginning. It was helpful, the Health and Wellbeing co-ordinator was helpful. They gave me practical help too - which forms to fill out... They gave me ideas of useful tools, like the door alarm would go off if PLWD opened the door."

"... Positive Steps Programme – I found out about things from other carers.... We all share information."

"Alzheimer's Society offered a course... very helpful. Things like putting power of attorney in place, health care, social care, finance."

“Carers [Wakefield] put me on a course with the Admiral Nurses – I learnt a few things... I also took PLWD on a course.”

“I’ve not taken any courses at the Alzheimer’s Society, but I’m considering it... but a lot of courses talk about things I’m not experiencing, as a lot of them are for people who have dementia at an older age.”

“Trying to visit groups or get help is hard; to get to them it’s office hours... couldn’t because I was working.”

Adapting to becoming a carer

The lives of all the carers we spoke to, both in one-to-one sessions or the focus group, were greatly impacted by dementia; day-to-day and work lives were affected, as well as health, wellbeing and finances. The carer role evolves over time and people have to adapt with the decline in the person they are caring for.

“I become a carer. It was something I didn’t expect I would be and didn’t think I’d be good at... Started from scratch – it’s like with children, you can read books, but really it is learning as you get on.”

“I retired a few years ago to look after PLWD and at an arm’s length, looking after PLWD’s [relative] who has different symptoms... there are different symptoms for different people... I’ve had three years of looking after PLWD - two years’ full time. I was too worried/stressed to leave as PLWD was doing random things like cutting through a lamp wire - really random things.”

“It’s a bit like grieving. I was looking forward to retirement... we could enjoy ourselves and this happened and you feel frustrated by that.”

“I don’t drink or go out like before. Life has changed in every way. Life is very different and I sometimes think when will I have my life back, but just get on with it.”

“I can’t plan very far ahead. I can’t book a holiday six months ahead as I don’t know what PLWD will be like.”

“It’s going to get tougher – I’ll have to do things differently. I don’t even know what that will be and how things will change.”

Day-to-day tasks are also challenging to carers; for some this means an increased reliance on relatives and friends, but also an increase in expenditure. The increasing financial burden is recognised by some businesses, who give discounts to carers. However, the way in which carers are asked for proof is not standard across the District and a carers’ passport has been suggested by a few people we spoke to as potentially overcoming having to carry around evidence. One carer also talked about her desire for Wakefield District to be a dementia friendly city and follow the good example set by Wigan Council.

“The biggest problem is going to the toilet. I can’t leave PLWD to go and PLWD won’t go with me. I have to leave PLWD with a friend I know in the shop... I have a radar key for PLWD but PLWD won’t go in with me.”

“My [relative] takes me food shopping every three weeks as it’s heavy.”

“I go to the Forget-Me-Not café once a month... it’s hard walking all uphill, so I have to get a taxi there and back as I don’t drive.”

“It costs me to go to the Carers Trust. The nearest one is in WF1. I don't drive, I would have to pay and can't afford it. A lot of things seem to go off in faraway places like Castleford; it's the same with day centres and care homes.”

“A lot of places give discounts to carers. The only slight issue is that there is no standardisation as a carer, so if you ask somewhere if they do a carers concession, some take it verbally, some want evidence... Some people abuse this... I carry around the PIP allowance... It would be good to have a carers' passport or a card that says I'm an accredited carer, but it probably wouldn't happen due to funding. It would prompt carers to go to more places/do more things.”

“People in the early stages don't want to say... may be coming to terms with it themselves... 98% of people will do something to make it easier for you.”

“I'd like Wakefield to be a dementia friendly city... like what Wigan Council have - Dementia Buddies where the person with dementia has a badge, wristband or something on their handbag. If you spot it and put your phone on it, you can get a name and contact number for the carer. We currently have the Herbert Protocol - but not everyone is able to say the words 'I'm lost'.”

Adapting to dementia in the family is also something that impacts on younger members of the family, particularly those who have a parent with early onset dementia. Accessing timely support is difficult and potentially costly, which negatively impact the child.

“My child was young when PLWD was diagnosed... got no help. The Admiral Nurse picked up on this, but nothing's come of it. I know the Admiral Nurses are under pressure... My child's under CAMHS - had one appointment with them. We rang them and we're now on a waiting list... don't take someone on if you don't have capacity. The school has been poor and suggested we fund for private counselling... PLWD is jealous of our own child. It's stressful. There's a need for support for children or grandchildren. Not groups - groups aren't right for everyone.”

Financial pressures

The financial pressures of caring were brought up by most of the people who participated in this project, many of whom have to juggle priorities based on what they can afford. Some people also felt that the systems in place or change in policies are unfair, which can lead to people feeling penalised, considering the millions of pounds they save the local economy⁹. This is further exacerbated when people discover that they haven't been given information that could improve their circumstances, at times making them feel that this is purposely done by the authorities in order to save money.

People were concerned with:

- Their own financial security including planning financially for the future and questioning if they can remain in their own homes:

“Carers give up work... What if something happens to him? What happens to me? Can we get any financial advice? I need help to plan for my future. The government don't want people to give up work to care - but what can I do? Private carers are very expensive.”

“Another carer I know, their [spouse] is in a home now – [that carer] is tearful, exhausted mentally, has had a drop in finance as everything's in their spouse's name – it's left them in a quandary.”

⁹ Carers Wakefield: <https://www.carerswakefield.org.uk/>

“The cost of help is astronomical and there’s not enough staff. It’s around £900 a week, so you basically lose your home... The carers are expensive and when you find out what the staff get, it’s just a tiny fraction.”

- Costs associated with care services (and these services not meeting the carers’ needs), the impact costs have on people being able to go out and enjoy life, the perceived unfairness of the system that decided who pays and who doesn’t, the perceived penalty of living with dementia as opposed to having another terminal disease, and the negative impact costs have on the mental health of carers:

“It would be lovely to know I could go away in two weeks... and that it isn't costing me an arm and a leg, knowing PLWD is safe and it would be a morale boost! “

“Respite isn’t accessible as you’d like. It’s not affordable. If you're poor you get it, if you're rich, you don't need it, if you're in the middle then you have to weigh things up and have to make value decisions.”

“I have to pay £34 for 9am to 3pm – they pick PLWD up and fetch him back. Its £16 an hour if they’re in the house - what can you do in two hours? I have to walk, take the bus – I’m racing against the clock.”

“His care - I have to pay out. Why can't PLWD be treated the same as people with cancer?”

“Carers come in now three times a day. I pay a lot for that. £15.65 per hour - I have to pay the difference... Now £18.25 per hour, £11 per half an hour, but I need two carers so it is £22 per half hour. I have to pay the difference... in total its £170 a week. There’s also double pay on bank holidays, so half an hour at 2pm costs £40... I worry about money. In my head I’m working it all out.”

- Costs and perceived financial forfeits associated with caring for the person living with dementia (with some once again comparing their situation to those living with cancer), such as being means tested, the changing rules around income, and the lack of beneficial financial information-sharing from the council:

“It’s not fair - we are means tested. If you don't have money you don't have to pay.”

“They've started to take attendance allowance into account now, as it’s still an income.”

“They only allow three [continence] pads a day, so we've bought some online. They cost me £60 for the pads. It’s all extra cost! Then to have a carer... so it costs £40 just to go to the supermarket... When my friend had cancer, the people come round four times per day and even got something for to hang round the neck for free if [person with cancer] fell. If I need something for PLWD I have to pay.”

“I try to do as much as I can, but its hard work trying to find it all out. You're not told that you can claim living allowance.”

“I rang the council who then said that the allowance has gone up to £16.24 per hour - why didn't they tell me that? If you don't query things, they don't tell you.”

Health and wellbeing

Mental health

Health and wellbeing of the carers we spoke to was affected in varying degrees and often by the condition of the person they are caring for. One family found themselves in a potentially dangerous situation, but on the

whole poor mental health was mostly commonly caused by physical and/or mental exhaustion and feelings of guilt, anxiety and stress.

“PLWD had knives all over the house and was ready to attack people except for me. PLWD was scared, frustrated... I wasn't scared because PLWD was so frail.”

“Mum went to hospital and PLWD's strokes got worse and worse with each one. Caring then fell onto me and I went into depression as it was so hard. I felt guilty if I had some time to myself and I was thinking of PLWD all the time, from the moment I went to bed and as soon as I woke up.”

“When I would leave I would cry because I felt guilty. I was physically and mentally exhausted... my stomach was constantly nervous and you're just dying for professional help.”

“At the moment I do everything - dress, brush teeth, toileting, washing, shoes, coat, get into the car, feeding, cooking, washing up – PLWD's unable to do anything like that... can't even pick up anything from the floor.”

“Sometimes PLWD drives me crazy. You discover parts of yourself that make you question yourself.”

Carers appreciating the funny moments and those who had a more positive outlook seemed to possess more mental resilience.

“The personality of the carer is important... the attitude.”

“You have to come to terms with what you have to do - some aren't as resilient... Don't let it beat it you.”

“Sometimes the funny things kept me going. PLWD's humour - PLWD was trying to do things that were from the old days.”

Physical health

Carers were also concerned about getting ill and the impact this would have on the person they care for, as well as other relatives who were either too young to care (or that they were protecting from becoming young carers) or would have to take time off work to help. Some people did not have relatives that appreciated the pressures associated with caring. The fear of not being able to care properly, also influenced the decisions carers would make about looking after themselves and it may be that some health professionals need to more actively offer help and encourage carers to think about themselves.

“I have to cope whether I am able or not.”

“Some carers get poorly - if the family aren't there then what do you do then? I've had to ask my children to take a day off work when I was poorly.”

“When I was poorly, I had no help at the time. My child is only a teenager and I don't want [my child] to be a young carer.”

“Mum has bad knees, if she fell, how would anyone know? There's a lot of people in this situation that have no one around them.”

“I'm now finding it hard to keep up with housework. I'm exhausted and get short with PLWD. It took me ages to ask my family for help - they come to see PLWD but don't really help. [A relative]

cooks tea once a week... I also care for my mum too – I'm not okay now that PLWD's not alright. I got upset... it's really stressful as my family aren't very understanding of our situation."

"I've suffered with pain and told the GP... came to the conclusion that it was stress and anxiety, but the pain has gone so I'm not bothered... I don't want anti-depressants. I need to be alert for PLWD."

Loneliness/Isolation

Isolation was also referred to by many of the carers we spoke to, many of whom were still coming to terms with the change in their lives and loss of companionship. However, support groups helped to relieve loneliness and contributed to a more positive outlook, with those that were inclusive of the person living with dementia also relieving barriers such as paying for care. Carers who were able to take time out for themselves also found this to make them feel more positive or better deal with caring.

"A lot of carers feel lonely and isolated... You're still young but robbed at heart and looking after someone you don't talk to much."

"...long days when it is just me and PLWD. We need more volunteers and more paid people - come and talk to PLWD, go for a walk. Who should provide that?"

"I've got into a routine... sometimes feel a bit down. Your life completely changes. I feel isolated on weekends... won't speak to anybody from Friday to Monday as I can't really speak to PLWD."

"The saviour has been the support group that the Admiral Nurses have set up – we meet fortnightly and it's a source of comfort, useful knowledge and companionship. You lose your companionship from this, you've been robbed, it's like a bereavement while they're still alive... a bit like living on your own... like having a child that doesn't speak - dress them, talk to them differently from you would in an adult conversation."

"I try to avoid isolation by [doing a sporting activity] twice a week and PLWD comes with me and it's a bit of exercise for PLWD too... I do things that helps a lot of people... I also go to support groups where they do activities including for PLWD... walking, lunch at a pub and PLWD's [relative] comes along too."

"Seeing other carers helps... I look after myself... exercise and massage."

"Memory Action Group, it's a self-help group... We see each other a lot, lots of them are part of the group and there are lots of days out. It's great because you and your loved one can go together... Positive Steps and Carers Wakefield is only for the carer; we wanted something for both... Also, other carers were worried about leaving partners at home alone, so this was the best answer."

Health and wellbeing of the person living with dementia

The health and wellbeing of the person living with dementia is also affected or challenged over time, due to changes in their cognitive function and behaviour.

"I think everyone is doing what they can, but I feel day after day that something's wrong with me. I carry on." (spoken by PLWD)

"We go to the hygienist and dentist for check-ups - last time PLWD wouldn't open their mouth to get the teeth cleaned. It's hard to clean PLWD's teeth and that could cause problems in the future."

"PLWD can't always see steps – PLWD made a mess of his arm falling."

The vast majority of the carers we spoke to encourage their loved ones to be involved in activities inside or away from the home in order to keep them stimulated and better manage mood or behaviour (one carer is even thinking about providing cognitive stimulation therapy). For those living with early onset dementia, again there is a feeling that services are not adequately geared to help them, but there have been some positive experiences relating to gyms and sports clubs that have encouraged participation.

“Women carers tend to do too much for the person they are caring for... doesn't give the person with dementia the chance to blossom at times. The more I see when we get together and do things, they [PLWD] light up. They can be shy and don't talk and then they come out of themselves.”

“We go to Sandal library, Hall Green Community Centre... Boccia bowling - it's ideal, shopping in town - PLWD wants to be out all the time... I'm always trying to find things to do... PLWD's gets agitated at home. I wear him out; he's easier to manage.”

“There are lots of gaps with exercise and the physical stuff. We're not elderly, we're not happy with chair exercises. The gym has been brilliant - said bring PLWD along to do some strength training.”

“PLWD is doing rugby again - disability rugby at Wakefield Trinity. I'm also training - it's good for both of us”.

“I make PLWD read aloud, make PLWD walk, I fill the house with people - it's stimulation... I have worked with children as a specialist... a lot in common with autism - I think of PLWD as my autistic four year old child.”

“Cognitive Stimulation Therapy isn't offered to us because of lack of funding. I've done that course and will offer it to people.”

Compassion and its impact on health and wellbeing

The health and wellbeing of those people living with dementia is affected by the demands on health services, with longer-term carers noticing a reduction over recent times in the level of visits by healthcare professionals and supply of resources/products. Even with those demands on services in place, compassionate care has been evident but unfortunately not across the board. More needs be done for compassion to be more prevalent, so that people feel that they and their loved one are being cared for with dignity, in addition to feeling confident to ask for help when they are experiencing difficulties.

“The District Nurse used to come every four weeks to check PLWD's skin. Now it's every three months... The carers always check and saw a pressure sore, the District Nurse said 'you'll have to send for a GP'. The GP was lovely and talked to PLWD and even asked me how I was. No one ever asks.”

“Some of the carers at Prestige went beyond. If they had time they would take PLWD out... When my mum came home, they would try to feed both my parents at the same time and tell me to go and get a cup of tea and relax for a bit. But you can tell some people are in it for the wage only.”

“The Admiral Nurses are always there for you; they want to look after us... they make a tremendous difference and we need more of them.”

“The pads that PLWD are on, they sent some that aren't as good to save money. The bed gets wet, PLWD is wet, the clothes are wet. I asked if we can have different pads and they told me that I have to fill in a diary and monitor drinking and frequency of urination, but we've already done all

this! The District Nurse said 'it's not God's given right you're given these pads... they don't give free pads to babies'. I said to the District Nurse the next day, 'I think what you said to me was out of order' and she told me that they're told to say that in training. I don't like asking for anything. It upset me."

"We were trying to get help but they [GPs] wouldn't come out at all. If PLWD needed blood tests we would ask if the GP could come as PLWD wouldn't leave the home and we got [a] look, 'we don't normally do that, can't you bring him in a taxi?' When they finally came, I felt obliged to thank them loads of times, as if they had done me a favour."

"There needs to be more training - people in the care home were very insensitive. I've worked in care – they don't always look at care logs... Care companies don't do dementia training except for one company - Flexicare. They just throw you in."

"The staff told off PLWD off for swearing... are they for real?! And they don't treat them with dignity, they told PLWD you've weed yourself. There's no dignity from staff... These people don't understand it and this is their job. They don't want to connect, they only deal with their bit."

"The GPs and nurses would come and do things that you knew they shouldn't do - they antagonised PLWD, even if I warned them about what not to do. It's like they never read the notes because I had to repeat myself to each person who visited. They talked over PLWD like a child, even though I would include PLWD in conversations and hoping that they would learn from my cues to include PLWD."

Accessing help

Accessing help was a massive issue highlighted by almost everyone Healthwatch Wakefield interviewed, who on the whole felt that their needs weren't being met. The following sub-themes emerged regarding accessing help:

Generational challenges

People felt that offers of help should involve the wider family, as generational differences can mean that older carers suffer in silence and/or relatives are also impacted negatively. They were also grateful for the help they received but at times this doesn't take into account how little time carers get in order to carry out everyday tasks. Organisations and companies that help or provide care also need to consider cultural challenges when it comes to older people living with dementia.

"Mum's decision not to accept help made it tough on her and us. Mum didn't want help even though she herself was poorly and weak."

"Alzheimer's Society do Side-by-Side; PLWD wanted to go to the pub but the guy they sent couldn't go in a pub."

"Alzheimer's Society have a sitting service... three hours, one day a week. I'm constantly clock watching and rushing to fit things in... My friend has a car, so at those times it's okay. It's no time if I rely on the bus."

"I know this sounds awful but they send foreign people in and then PLWD gets angry because PLWD thinks the carer is taking the mickey out of them... PLWD would chase them out. We called Prestige who said that's not the first time. The carer would have to leave after ten minutes as PLWD would chase her out. It's annoying as we're paying and they leave after ten minutes. The service needs English speakers for this older generation."

Social care services

Social care services are perceived by the carers we interviewed as not meeting the needs of people living with dementia or their carers, or indeed having a good knowledge of the different types of dementia and the impact this can have on requirements around care. Access to social workers was also an issue mentioned by a couple of carers, who found it hard to get through to speak to someone and even then, the casework based system mentioned seems to make it hard to access help in a timely manner.

"I need help around the house... A social worker's coming soon; their help might be more of a hassle than help... I'm going to fight for respite."

"PLWD sleeps downstairs on the sofa. Social services have said, have you brought the bed down? Where? How? It's not like PLWD's bedridden. Social services are talking to me like PLWD's an old person. I could do with a bedroom and bathroom downstairs - until you're desperate it seems that... it's all reactionary and no proactivity... I tell you who was brilliant - Age UK. They helped me get money to improve some things at home".

"The DN (District Nurse) came and then social worker who said PLWD doesn't need continuing healthcare. PLWD doesn't need nursing because PLWD's not poorly! PLWD can't walk, can't sit up straight, needs feeding..."

"It took four calls to get through to the social worker recently. She told me 'I've written PLWD off now' - apparently once they've dealt with you, they finish your case."

Different types of care

Respite care doesn't meet the varying needs of the people Healthwatch Wakefield interviewed. There are barriers to overcome such as time, planning, or staff resources and it is difficult to access. For some, it seems to have become increasingly difficult to access over the past few years. Respite care is something the vast majority of carers want or need, but it adds to financial pressures and negative mental or physical health. Carers have lost confidence in the system as a result and having to pay for respite only compounds feelings that dementia is not considered a terminal disease in the same respect as other terminal diseases.

"It's so expensive and we shouldn't have to pay care homes. It's a disease - if you had leprosy you'd get help for nowt."

"A few years ago the Memory Clinic suggested I try respite. The social worker came and arranged four weeks a year. At the time there was a new care home, so all the beds were available. For first 18 months it was fine, but after that I couldn't get PLWD in... no beds or vacancies. Now I have to wait to book until two weeks before and some places it's one week, then there's the assessment before they decide if they take PLWD. As PLWD has got worse, they couldn't take PLWD due to staff resources... needs feeding, drinking, everything."

"I want to know what you're going to do about affordable, accessible respite care. I don't see what their plan or strategy is for respite - is there a strategy there?"

"PLWD just needs a home that can give him care... hasn't been to respite for 12 months - all homes we've visited have said they can't cater for his needs. I don't get any time off at all. I have to get up if I'm poorly or not. If I'm poorly I manage on my own."

"PLWD went to one home... got really dehydrated and had water infections and PLWD's mouth was sore and dry inside."

"One respite didn't give PLWD their medication... I could tell some weren't given as too many meds were left in pack."

Another factor that impacts negatively around respite care is the lack of continuity when it comes to professional caregivers. This impacts the person living with dementia and the carer as lack of continuity is confusing, can lead to negative behaviours and hampers the transferral of useful information between the carer and the provider¹⁰.

“What most carers want are PROPER respite opportunities - afternoons on your own and weekends away. You could do it on your own steam; ring an agency but it might cost £15 an hour... I think the council does support people on low incomes... I don't understand the system and I won't navigate it. Also, if you do it more than once, you get a different person who won't know PLWD. You don't want to put them in a home - that's for old people, how do they treat them in a home... don't even know if PLWD would sleep on their own - will PLWD cope? Also, an afternoon isn't enough.”

“There are too many people who come out; it's not the same people each time.”

“[The person] who offers care for PLWD is consistent and that's why PLWD is doing so well.”

One carer suggested the implementation of a co-operative system that could potentially address cost, access and continuity of respite care.

“What is it that could make it happen? A pooled resource amongst our specific group of carers - someone willing to be employed by a group and we then book slots with that person... but then there's all the associated HR. This would probably be cheaper, maybe £10/hour and it would be the same person doing it, so we know that person and vice versa. Is there an organisation that could help us to achieve that? ...The council could employ someone and then the group could fund 50% and the council pay 50%... cheaper than the person [PLWD] going into a home. That person would learn/be well trained and get to know you. If we could access that help... would actually help with stuff that weighs carers down.”

As the dementia needs become more complex, some carers have also found it is harder to find appropriate professional help that can help them cope and keep their loved one at home. As the condition of the person living with dementia deteriorates, some carers find their loved ones experiencing unsuitable and detrimental help, particularly between care homes and Pinderfields General Hospital; views that have been echoed by some health professionals we spoke to.

“Once dementia is past a certain point, caring companies don't come anymore so they get worse and you're left on your own again. You have to get them in a home at the right time. PLWD had to stay in an assessment centre and there was nowhere for PLWD to go due to demand... So few places... PLWD needed a nursing home and they're more expensive and don't usually deal in dementia. The hospital wouldn't keep PLWD so we'd go back to the assessment centre and then when PLWD's condition would get worse... would go back to hospital and so on. PLWD would be there [in hospital] by them self until the family could get there... People with dementia/Alzheimer's need a holistic centre. They get even more confused by all the to-ing and fro-ing. They need a dementia ward in the hospital... Feels like they pass them back and forth to speed up the death process... I felt like coming there one night to take PLWD home.”

“There are issues with care homes sending people to Pinderfields... Inappropriate hospital admissions - most people are living with other co-morbidities... is it appropriate sending them to hospital as when they come back, they're worse. It's hard for the care homes as they are worried; damned if you do and damned if they don't and they don't feel it is their decision to make. People are sent back and forth - it just makes them worse.”

¹⁰ Why care continuity is so crucial for people living with dementia: <https://www.thegoodcaregroup.com/news/why-care-continuity-crucial-people-dementia/>

“Certain wards in Pinderfields need to improve; some just put someone's drink or food in front of them and that's it - no help... In A&E, the person with dementia should be fast-tracked as they find it massively confusing. They're too busy to take notice - people are trying their best but resources are limited.”

“Hospitals are not the right place, for example a low level of falls is not a good measure; it just means that they're good at keeping people in bed. A better ward is one where they get people to do as much as they can.”

There are also concerns for people living with early onset dementia, especially with regards to care not being appropriate for this younger group of people.

“What happens when the carer can't cope and the person they care for is only 60? You're not going to be in a home with 90 year olds... Not respecting people's dignity - how would PLWD fit in a care home where people are so old? They're asleep in their chairs. It doesn't feel right... Is that a viable alternative for people like us? A 24-hour care home? We can't put them in settings for vulnerable adults or those with mental health issues as that isn't right either.”

Professional healthcare

Some carers brought up the subject of their GPs. Some were happy, but more criticised the lack of continuity with GPs, along with language used in correspondence, accessing appointments and annual dementia reviews. The latter being viewed as somewhat arbitrary, as the consultation would not feel informative or results driven. Generally, the lack of information or apparent knowledge surrounding dementia as well as some poor behaviour displayed by some GPs led to a lack of confidence by some carers in their GP's ability to help them and their loved one.

“PLWD doesn't have regular check-ups with the GP, but the GP is brilliant. He didn't just refer us, he sent us to Hemsworth to see a gastro guy as PLWD's recently been diagnosed as coeliac. He's a very understanding GP. We have also seen another GP who is very good.”

“The GP annual dementia review is somewhat of a joke; it's a lip service. I got a letter, 'Dear [name], your annual dementia review is now overdue' - they're already criticising me even though this is the first I've heard of it, is it my fault... they haven't given me an appointment to be overdue from! I then phone up to make an appointment – 'oh we don't have the lists out'. You can't book an appointment and then have to remember to book an appointment after you get back from being away... Then you see the GP – 'how are you doing? How's the meds? What is PLWD like? What are you like?' They're writing it all down. Why aren't GPs telling me about what's out there? GPs are learning more from us rather than the other way round. Sometimes I feel like testing the system by saying it's all terrible... what would happen then?”

“GPs don't want to know at all... GP annual check – we've not been for a good while. They were good to start with.”

“There's a fear that there's no joined up care. It bothers me because it feels like a box ticking exercise. Each GP service should have a dementia specialist, or even more, an end of life specialist.”

“The GP in Crofton (Crofton & Charleston Medical Practice) were unwelcoming... not enough chairs in the GP's room... the GP wouldn't bring in another chair. It felt like the GP was thinking you've got this problem, I'm not going to do anything for PLWD... basically, I don't want you to get comfortable and waste my time.”

“Once they know they can't help, you're more or less a time stealer. The person they are seeing and the carer are struggling with this thing.”

Admiral Nurses are a much valued source of help and carers would like to see more in the District to help meet demand. In contrast, some carers have negative experiences of other health professionals, who have been critical or dismissive, or who's actions have had a very detrimental effect on the person living with dementia.

“The Admiral Nurses are there for people, especially those in crisis.”

“Admiral Nurses are a God-send. Without them I don't know where we'll be. Social services take a month to call you back unless it's an emergency. Admiral Nurses are the only thing that hold it all together. They understand the subset of Alzheimer's and what we need.”

“If PLWD changes, I'd call the Admiral Nurses, but it's hard to get hold of them, they're so busy.”

“The Admiral Nurses sorted a wheelchair for PLWD, but forgot to come three times.”

“The Admiral Nurses are too busy – they'll make themselves sick.”

“The nurses didn't understand dementia. I haven't time to explain things to them... made me cry three times.”

“They gave PLWD something else (turned out to be an anti-psychotic which PLWD should never have been on) and PLWD didn't wake up for a week! Like PLWD was in a coma when PLWD came home! I called the doctor the next day who told me to call an ambulance... Went to Pinderfields A&E which was a waste of time... but once on the ward, they were nice... Pinderfields - the minute they find out they've got dementia, they're not interested. It's like they assume they're all violent... They had given it to sedate PLWD to stop PLWD from walking around... When we came home, we were given a bottle of meds, which was not on PLWD's list of medications. We asked the hospital when to give PLWD the meds, who said oh it is on there... the nurse had an attitude. I wanted to know what the meds were. The nurse didn't know and wasn't helpful and didn't call me back... PLWD's speech went straight downhill after that... went downhill very quickly - even the Alzheimer's nurse said that he had never seen such quick deterioration.”

The Admiral Nurses are also aware of the huge demand for their help and would like to do more in order to meet the needs of people living with dementia.

“We can't physically cover all this work and yet there's a huge need, not just for information, but also the complexity of the people we are seeing. We need time to spend with them; there's no time to do in-depth consultations, counselling or couple work.”

There were also comments regarding Occupational Therapists, who aren't perceived to always provide viable solutions or aren't creatively thinking about how to overcome issues that cause problems for carers. In addition, decisions don't always take into consideration temporary setbacks, such as an illness, but can result in a permanent and negative domino effect; which for the people we have spoken to, impacts on the carer's health and finances and on the health and wellbeing of the person living with dementia.

“The Occupational Therapist came out around two/three years ago. PLWD was still mobile then, but getting up the stairs was tough. We had trouble getting up and down the stairs. The Occupational Therapist said they won't put in a stair lift in for people with Alzheimer's. I had to put it in myself and PLWD's been fine with it. We got a seatbelt on and then another one that overrides PLWD undoing the belt. It has foot straps on too.”

“Then there was the bath seat. The Occupational Therapist came out at a time when PLWD was poorly, sleepy and sloping to one side. She said PLWD couldn't go in the shower or use the stair lift anymore. PLWD wets the bed, so needs a shower. I disagreed with the assessment. The Occupational Therapist rang two weeks later as they do and mum asked for another assessment. The Occupational Therapist came out again and altered the assessment and said we could do what we had done before, just that PLWD couldn't use the stair lift anymore. If PLWD stays in bed, there's a deterioration. The Occupational Therapist altered it, but the care company won't alter it back, so PLWD's now based downstairs... Because PLWD doesn't move as much... always lying down. Led to the deterioration of PLWD's condition... just lays there, eyes shut. It's isolating for PLWD. From July I've felt upset, not depressed, upset.”

Joined-up working

There is a need to improve communication between departments and organisations in order to effectively help people living with dementia. Some carers also feel frustrated by the perceived competition between professionals and/or organisations and would like them to more openly work together to benefit people living with dementia and their carers – this would help to build the confidence of service users in the provision of services available to them, but potentially also reduce the amount of overlapping of information or events.

“I called a receptionist in the same building as the Admiral Nurses, who didn't even know about the Admiral Nurses.”

“More services and charities need to speak to one another; you get a leaflet about an event and then get another leaflet from another charity about the same event... we need joined up services.”

“Everyone seems to work in pods and not working together - Dementia UK, Alzheimer's UK, NHS.... Everyone's protecting their own backs and own position... doubling up on things rather than focussing on a variety of things.”

“I found the Alzheimer's Society not very supportive - no you can't access banners (?). Instead it should have been, 'how can we help to promote this'? Alzheimer's Society support workers are brilliant – it's higher up that's more difficult.”

“There's a lot of internal fighting - people/organisations protecting themselves/ their own services... You shouldn't be doing that with that organisation - sorry, but I want to do things to help people using the service! If they pulled (pooled) their knowledge and resources together, you might wonder how much better things can be and not duplicating info and communications. The hospice is really good, but everyone's wary of each other. Even when in same room, professionals from different organisations don't talk to each other. Why don't organisations and professionals talk to each other? It prevents the service from being more fluid. It's almost like office politics - each one has so much to give but...”

Advanced Care Planning

Advanced care planning (ACP) is the term used to describe the conversation between families and carers and those looking after them about their future wishes and priorities for care. The main goal is to clarify peoples' wishes, needs and preferences and deliver care to meet these needs.¹¹ Healthwatch Wakefield asked carers about ACP; responses were mixed with some having never heard about it, some people feeling positive about forward planning, others not wanting or feeling able to tackle the end-of-life subject matter, and some people questioning the value of ACP.

“I don't know what an advanced care plan is.”

¹¹ Advanced care planning: <https://www.goldstandardsframework.org.uk/advance-care-planning>

"I know the Admiral Nurse wants to talk to me about the future. I'm constantly torn between living in the here and now and looking forward and trying to work out what we need or might need. Some conversation about the future wouldn't be a bad thing and I'm interested in the concept of what ACP is, as I don't know how things will be in the future. They [the council] need to know what resources they need to deploy, but it's a hard question to answer as every person is different and we don't know the speed of progression and what you can or can't cope with. Everyone has a different breaking point."

"I don't think I'm at that point yet... Something that people won't have even thought about, so it's a good question to ask."

"No, not yet... another thing that is quite settling. It's not a nice subject but good. I'd welcome that kind of support really to avoid being reactive and be more proactive. Then it means that decisions are not based on emotion... Putting my head in the sand won't make it any different."

"The future? We've decided on do not resuscitate."

"The Annual Dementia Review is the only contact I have with the service. I'm not worrying about that [ACP] right now and what can you do? I believe you help yourself as much as you can."

"I don't want to think about it... I want to plod on in my own sweet way."

It was interesting to note the comments of health professionals' views of ACP, which confirmed that ACP is beneficial, but only if it is up to date and currently relevant to the person living with dementia. Their views also echoed that of some of the carers we spoke to when it came to not wanting to discuss ACP or comparing dementia to cancer.

"Advanced care planning should be in place to make sure people are not just sent to A&E. It's only as good as the decision made there and then as prognosis is unpredictable; there's a place for them but they need revisiting and revising."

"A lot of patients don't want to do Advanced Care Plans - this should not be a benchmark that has to be done. You wouldn't give a person with cancer an Advanced Care Plan."

"Because of the gap in the entire provision, there is not time. There needs to be a proper pathway for dementia... discussions about AC Plans is not appropriate. The actual use to the person is negligible. We tend to be hitting people at crisis point and it is often an odd question to be asking."

Conclusion

This report has found that the services in place that help people living with dementia and their carers are much valued. However, the gap between service provision and the needs of people living with dementia are wide, demand seemingly outstripping supply and having a negative impact as a result on health and wellbeing. Dementia is viewed as being less important as other terminal diseases due to the length of time it takes to obtain a diagnosis, the perceived financial penalties placed upon the carer, difficulties in accessing various types of help and the way in which the disease is handled at the late stages, particularly the relaying of a patient between the care home setting and hospital.

People are keen to do as much as they can for their loved ones, but need to feel supported in doing so. They value the help they receive from various charities, carers' groups and specialist healthcare professionals, but they need more as access can be an issue.

Limitations

All the people we interviewed or participated in the focus group were of White British or White Other ethnicity. We did try to capture the views of people from other ethnicities, but were unable to do so due to limitations on access to groups.

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Disclaimer

Please note this report relates to the experiences, thoughts and feelings of participants in this piece of engagement work and may not be a representative portrayal of the experiences of all people who care for people living with dementia or are people living with dementia. It is an account of the specific experiences of the people we interviewed, either as individuals or as part of the focus group.



About us

Healthwatch is the independent champion for people who use health and social care services. We're here to find out what matters to people, and help make sure their views shape the support they need.

There is a local Healthwatch in every area of England. We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that the government and those running the services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.

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