



Dementia Report

Experiences of Health and Social Care services in Derbyshire from the perspectives of people living with dementia, their carers and family members



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1. Thank you

Healthwatch Derbyshire would like to thank all participants who gave their time to talk to us about their experiences of health and social care service in Derbyshire in relation to dementia care. We also extend our thanks to the many groups and services who supported and cooperated with this engagement activity.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, family, friends and carers who have experienced health and social care service in relation to dementia care but nevertheless offer a useful insight. It is important to note that the engagement was carried out within a specific time frame and therefore only provides a snapshot of patient experience collected at that point in time. They are the genuine thoughts, feelings and issues that patients, families, friends and carers have conveyed to Healthwatch Derbyshire.

The data should be used in conjunction with, and to complement, other sources of data that are available.

3. Background

Healthwatch Derbyshire is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

Healthwatch Derbyshire was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

3.1 What is dementia?

According to the Alzheimer's Society, "the word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language, and can often cause changes in mood, perception or behaviour. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. The specific symptoms that someone with dementia may experience will depend on the parts of the brain that are damaged and the disease that is causing the dementia".

Types of dementia may include:

- **Alzheimer's disease:** This is the most common form of dementia; this is when abnormal proteins cause brain cells to die and early symptoms are often associated with memory loss
- **Vascular dementia:** The second most common type of dementia; this can occur when the blood supply to the brain is interrupted, for example, after a stroke, and causes problems with thinking and planning
- **Dementia with Lewy Bodies:** This type of dementia gets its name from the tiny spherical structures that develop inside nerve cells. Symptoms often include fluctuating alertness, hallucinations and problems with movement
- **Frontotemporal dementia:** Damage occurs first in the front and sides of the brain; personality, behaviour or language are initially more affected than memory
- **Young-onset dementia:** People who are diagnosed with dementia before they are 65 are said to have 'young-onset dementia.' They may have different challenges to older people, partly due to their age.

For more information, visit the Alzheimer's Society:

https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia

4. Rationale for the report

To ensure a diverse range of individuals are able to share their views on local health and social care services, Healthwatch Derbyshire undertake targeted pieces of work, paying specific attention to those who may otherwise struggle to be heard. The Intelligence, Insight and Action Sub Group of Healthwatch Derbyshire, who regularly appraise all the comments and experiences received by the organisation, recommended this engagement priority to further explore comments received by Healthwatch Derbyshire and enable Healthwatch to have a greater understanding of the care and support people living with dementia (PLWD) and their carers/family members experience.

5. What we did in brief

To collect consistent information across the county, a series of questions were developed to provide a framework for discussions. These were based around the 'Well Pathway for Dementia' (see appendix 1, p34) which was developed by NHS England who are working towards ensuring people diagnosed with dementia by 2020 have a better experience of health and social care support, from diagnosis through to the end of life. The 'Well Pathway for Dementia' provides a framework to align and co-ordinate the contribution of health and social care partners to meet key commitments which include: improving diagnosis, support and care after diagnosis, enabling people to live well in their own homes for longer, end of life care and education, training and workforce. More information can be found: <https://www.england.nhs.uk/mental-health/dementia/>

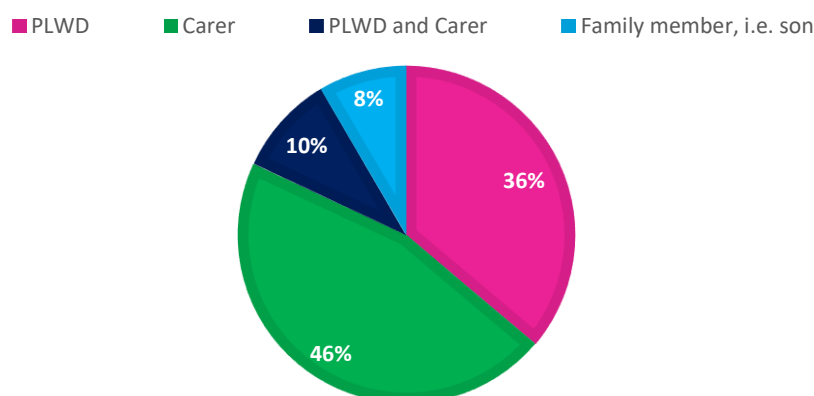
5.1 Methods of engagement:

All engagement officers (EOs) undertook a Dementia Friend's training session prior to engagement starting to ensure a good understanding of dementia.

We collected people's experiences in a number of different ways over a four-month period (September 1st 2017 - January 19th 2018):

- **One-to-one interviews:** We initially visited different groups and services to establish contact with PLWD and their carers and/or family members. A date was then set with these individuals for a one-to-one interview to take place. A total of 50 interviews took place
- **Group discussions:** The EOs visited and facilitated discussions at the Derby and Chesterfield Dementia Engagement and Empowerment Project (DEEP) groups, the Working Age Group and a Black Minority Ethnic (BME) Forum. Approximately 47 participants took part in these discussions
- **Dementia-Friendly survey:** We produced a short survey containing four questions to capture experiences directly from PLWD. This was completed by 13 PLWD
- **Professionals' comments:** We welcomed feedback from professionals.

The chart below shows the composition of the participants:



Some of the feedback was provided by PLWD independently, whereas some feedback was provided jointly by the PLWD and their carers and some feedback was from family members who did not class themselves as carers.

A number of considerations should be made when reading the findings, which include:

- Some participants struggled to recall all elements of their experience
- To ensure confidentiality we have removed information that we feel could potentially lead to the identification of any of the participants

- Some of the experiences date back over 12 months ago, however all participants were currently accessing services at the point of engagement.

6. Key findings

Preventing well:

- Participants highlighted the importance of early education to raise awareness and understanding of dementia
- There was an expressed need for more information around all types of dementia, not just Alzheimer's disease which seems to be the main focus
- A high number of participants discussed how they managed as a family for a long period of time without help, as they were unsure of the signs and symptoms
- Participants felt it was important that all the signs and symptoms were communicated, rather than focusing on just memory loss, as this would make it easier for people to recognise the signs and seek professional advice at an earlier stage
- Participants under the age of 65 felt that it was difficult to access information about young-onset dementia. It was also felt that images used for literature and campaigns portrayed a negative image, and sent out false messages that dementia only affects older people.

Diagnosing well:

- A high proportion of participants felt their initial concerns were listened to by a professional and a referral was made to a Memory Assessment Clinic (MAS Clinic) for further investigation. However, some carers and family members felt professionals did not always listen to the concerns they expressed around their loved ones, which caused a delay in being referred and ultimately receiving the diagnosis
- Some participants under the age of 65 felt their symptoms were sometimes "downplayed"
- Most participants felt their diagnosis was delivered in a compassionate manner, but some described it as "very matter of fact"
- Most participants received their diagnosis within a few months, and those who waited longer were being monitored during this time
- The BME community felt that they had experienced longer waits for a formal diagnosis due to language barriers and cultural differences
- A high proportion of participants felt they received too much information at the point of diagnosis and felt it would be more beneficial to have information around their diagnosis once it had "sunk in"
- A number of carers and family members felt there was no opportunity to ask questions privately about their loved one's diagnosis
- Not all participants were referred/signposted to sources of support following diagnosis. However, those who had been referred/signposted, had mixed experiences of the support received

- Most participants explained they did not have a care plan in place, or were unsure whether one had been developed. Some participants did have a care plan in place with Derbyshire County Council (DCC) or were linked with the Derbyshire Dementia Support Service (DDSS)
- The experiences of reviews within the first year varied; some participants had a yearly review, whereas some participants had no update of their diagnosis.

Supporting well:

- There were mixed experiences of accessing support from health and social care services, with many highlighting difficulties
- Participants who were linked in with their GP or a health professional spoke positively of the support received
- Experiences of dementia key workers and 'dementia- specific' wards within hospital settings were positive
- There appeared to be language barriers especially within hospital settings for participants from the BME community
- There was a perception that some professionals working with PLWD in a wide range of services had not been adequately trained to meet their care and support needs
- In terms of care at home, experiences were mixed depending on the service provider. Participants who used care services from DCC spoke positively about the care received and the level of training from the staff
- Participants highlighted the importance of continuity, routine and training for homecare staff
- Information and support from DCC and occupational therapists (OTs) was valued by participants with regard to falls prevention and home adaptations
- Participants appreciated the Safe and Well checks offered by Derbyshire Fire and Rescue Service (Derbyshire FRS), which provided reassurance
- The support/activities provided by independent groups and day centres were spoken highly of by all
- The DEEP groups were praised by participants
- DDSS was spoken about negatively in terms of participants feeling that there was poor facilitation, inappropriate activities and a lack of one-to-one support. Participants explained they would prefer the groups to be a place of meaningful support with activities that are stimulating and educational. Some participants did share positive experiences, and others felt that the service was "getting better"
- Participants explained they would prefer to have a named person to go to for advice and support as there is often 'too many' organisations that offer support which makes the process of 'knowing who to go to' fairly confusing
- Participants under the age of 65 felt there was a lack of support and activities available for young-onset dementia.

Living well:

- Most participants identified themselves as carers, however there were mixed experiences of having a carer's assessment

- Carers spoke of initially being unsure of where to go for support and therefore had to become very proactive in finding out what was available to them
- The co-ordination of services to support carers was described as ‘disjointed’
- Participants who were self-funded explained they were often just given a booklet or leaflet on the support available with no further help and often felt they were left to “fend for themselves”
- Participants felt unsupported in their role as a carer and some participants explained their caring role had an impact on them being able to look after their own health
- Responses were mixed regarding the carer’s emergency card, however those who were not aware of the card explained they would have found it useful
- Most participants who had registered as a carer with their GP surgery spoke positively of the support received
- There seemed to be a lengthy process in accessing respite care, however once the support was in place it was spoken positively of and valued by carers
- Experiences related to Continuing Healthcare (CHC) were poor, with participants explaining the process is difficult to understand
- Participants mainly spoke positively around Dementia Friendly Communities (DFC), with most participants explaining ‘it is getting better’
- Experiences around Dementia Friendly Swimming sessions and Dementia Friendly Walking were all positive.

7. What people told us

Experiences of people living with dementia over the age of 65

7.1: Preventing well

Early education:

Participants felt that early education is important to enable people to become more aware of dementia and understand that it is not a natural part of ageing and that it could happen to anyone.

Participants felt that there was not enough information around risk reduction and the early signs of dementia. Some said that “it is getting better” however, others explained that “if it isn’t something that is affecting you, you don’t really take note or talk about it”.

Sample of comments:

- *“I don’t think people link health and dementia together; I feel people believe there is nothing you can do”*
- *“I think people believe it is part of getting old”*
- *“I think people are frightened and therefore do not particularly want to look at what they could do to prevent dementia”.*

Information around all types of dementia and the different symptoms:

Participants felt there should be more awareness around all types of dementia, including the different signs and symptoms.

It was felt that there is a lot of awareness raising around Alzheimer's disease, and although it is understood that this may be the most common form of dementia, participants felt there was not as much information available for the other forms, such as vascular dementia and frontotemporal dementia.

Participants felt there should be more information around the different signs and symptoms as many people believe it is solely around memory loss which many participants explained that this was not their first sign.

The majority of the participants firstly noticed signs which included difficulty completing DIY tasks, withdrawal from social activities, changes in behaviour and becoming lost in familiar surroundings.

Sample of comments:

- *"There is not enough information on all types of dementia; it all seems to be around Alzheimer's. For my mum it was not around memory loss, she had frontotemporal dementia where the signs were around speech and randomised comments but we were not aware of this at the time"*
- *"It is not always about memory loss, it can be mood changes and putting things in order as it was for my husband"*
- *"If people knew more about the signs they would be able to seek help and get diagnosed more quickly, but I think it is also about having the confidence of knowing what to do"*
- *"He had always been good with DIY but he began to struggle with this and had difficulties with problem-solving and was becoming very frustrated at things"*
- *"I suppose it was the memory loss but this was not the main issue; it was his behaviour and getting lost"*
- *"I think people should be thinking about symptoms other than memory loss"*
- *"Maybe if there was better awareness you would go to your GP sooner and it would not be so dragged out and feel so long"*
- *"I hesitated about seeking medical help due to conflicting symptoms of depression".*

7.2: Diagnosing well

➤ Before the diagnosis

Unsure of the early symptoms and when to seek professional advice:

As reflected in the preventing well section of the report, many participants felt there should be more information around other symptoms of dementia, rather than a focus on

memory loss.

Once the signs had been recognised by the individual, family or carers, quite a few participants explained they had “discussed it as a family” with many continuing to “manage as a family” for a lengthy period of time before seeking professional advice. As some participants explained, “it was a sore subject to bring up” and “it was just little things to start with”.

Most participants visited their GP quite quickly or at least within the first year of noticing the signs. Those who waited much longer explained this was due to “being unsure of the signs” and in a few cases they had put it down to age, stress or depression.

Initial discussion with a professional (mainly a GP):

A high proportion of participants did feel their initial concerns were listened to. Most GPs carried out a Mini Mental State Examination (MMSE) and then made a referral to the Memory Assessment Service (MAS) clinic, whereas some participants were told to see how things go and monitor any changes.

Sample of comments:

- *“Yes, they arranged for the usual tests; they did a paper-based cognitive test at the surgery and checked for urinary tract infections and vitamin deficiencies as this can eliminate other things”*
- *“Very much so, all the staff I encountered pre-diagnosis were excellent and very thorough”*
- *“I did not feel my concerns were taken seriously initially by the GP as it was put down to old age and it wasn’t until we returned to the GP with the same concerns that a referral was made”*
- *“We had to wait 18 months before anything was acted on. You shouldn’t have to keep going back and have to ask for a referral. There should be continuity with GPs too; we saw a different doctor each time”*
- *“We went to the GP who did a test with items on a tray. We were told nothing was wrong as he was in the normal range”.*

The views of carers and family members:

Some carers and family members felt professionals did not always listen to the concerns they expressed around their loved ones, which caused a delay in being referred and ultimately receiving the diagnosis.

Sample of comments:

- *“Professionals should listen to the family as we are with them and can see the changes properly. When people go to their doctors they could be at their ‘best’ and the doctors may not always see the person when they are manifesting dementia symptoms”*

- *“We went to the GP who did a memory test and he sailed through it. It was then put down to old age, but when you have lived with someone for so long you know when something isn’t right. We left it for a few months, we ignored it and hoped it would go away”*
- *“When pushing for doctors to listen, you have to trust your instincts as you know when there is something wrong with your husband or wife. You should not have to keep putting your foot down to get a response and a diagnosis”.*

➤ Receiving the diagnosis

Referral to the MAS clinics:

Most participants explained they underwent various tests and scans with a specialist, including computed tomography scans (CT scans) and magnetic resonance imaging scans (MRI scans) to determine their diagnosis.

Most participants felt their diagnosis was delivered in a compassionate manner, whereas some participants expressed a negative opinion of how the diagnosis was delivered.

Sample of comments:

- *“The consultant seemed very positive and caring”*
- *“I felt the delivery was tailored to suit us”*
- *“It was very cut and dry; this is dementia and you have to deal with it”*
- *“It was just a matter of fact for the doctor but for us it was devastation. They need to think of this. When my mother had cancer all the professionals were extremely compassionate and understanding. Why is this not always the case with dementia?”*

Length of time from referral to receiving a diagnosis:

Most participants felt that this happened quite quickly with the majority of participants receiving their diagnosis within a few months. Some participants had to wait much longer. But most of these participants explained that they were under a specialist and were undergoing various tests.

Sample of comments:

- Most participants explained that “it happened quite quickly”
- “My diagnosis was completed in 10 months; there was a lot of confusion over the scans and the wait just felt too long”.

Information following diagnosis:

Most participants felt they received too much information following the diagnosis and it was felt that it would be more beneficial to allow the diagnosis to “sink in” first, and then have the opportunity to receive information around the diagnosis and the support available.

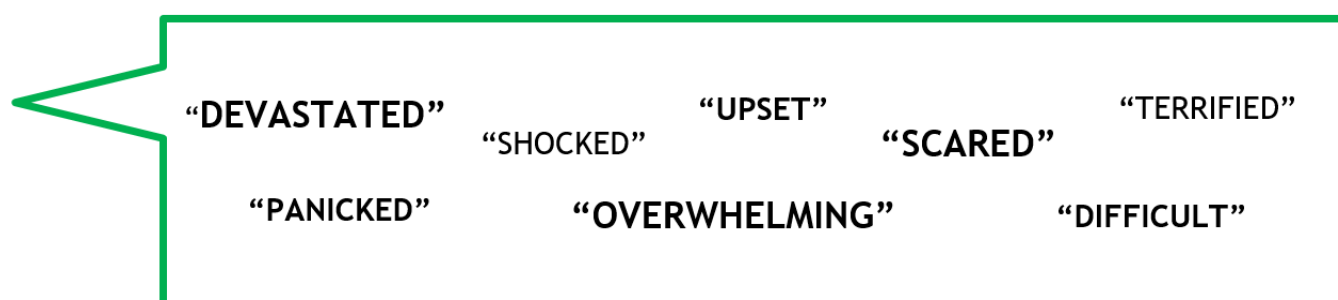
Many participants did not have concerns immediately after diagnosis and felt they needed time to “come to terms with the diagnosis”. Some carers/family members who did have immediate concerns felt there was no opportunity to ask questions privately away from their loved ones.

Some participants had received no information regarding their diagnosis and a few were unaware of the type of dementia and had undertaken their own research. It was felt by some participants that there was no clear answer to the questions they had around progression of the disease.

Sample of comments:

- *“It was like a lead balloon; it was such a shock and at that point we found it very difficult to digest any information that would be relevant to us later”*
- *“You are given too much information covering everything. It would be useful to receive only the information that you need, to make it easier to take in and understand”*
- *“There was loads of leaflets, it seemed bewildering at first but I know the information is somewhere; it is just knowing what leaflet to look at first to find what I need”*
- *“It would be best to have a follow-up a few weeks after the diagnosis to be able to ask questions and understand everything better”*
- *“I was a bit shell-shocked, so I didn’t ask any questions at the time but then I never got the chance to ask my questions because we didn’t see the consultant again”*
- *“I wanted to ask questions but I felt this was inappropriate in front of my father. I felt there should have been another opportunity given for family members to ask questions”*
- *“It was very difficult to ask questions in front of mum when she was still in denial”*
- *“There was no clear answer to the questions we asked such as the progression, understandably they cannot give the exact date as everyone is different but an estimate would have been good, as this has affected our life insurance”.*

The feelings of people following diagnosis are documented below:



Signposting to support following diagnosis:

Not all participants were referred to further support following their diagnosis. Some participants who were referred found it useful.

Some participants were referred to the Living Well Programme, although this was not consistent for all participants. Those that attended the programme spoke highly of it and explained how informative they found the sessions.

Some participants (mainly in Erewash and South Derbyshire) explained the Q&A sessions organised through Derbyshire Healthcare NHS Foundation Trust (DHcFT) were very helpful.

Sample of comments:

- *"No one was helping us come to terms with the diagnosis; it has felt like a bereavement"*
- *"We thought getting the diagnosis would help us; the MAS clinic became this magical place where we would get the information and help we needed, but this was not the case"*
- *"There is a lack of professionals involved post-diagnosis. I have contact details for a community psychiatric nurse (CPN) and dementia nurse but you have to chase it up yourself rather than them contacting you which would have been better"*
- *"Straight after the diagnosis the consultant took us to meet someone from Making Space and we were then told all the facts"*
- *"It was nice to meet people who are going through the same as you; we also learned a lot and received a lot of information" (Living Well Programme)*
- *"It brought both carers and PLWD together and we were in separate rooms which allowed us to share experiences without the individuals getting upset when discussing certain subjects" (Living Well Programme)*
- *"They give you a chance to ask questions" (Q&A sessions DHcFT)*
- *"They are good as you can share tips with other carers" (Q&A sessions DHcFT).*

Care Plans:

The majority of participants responded "no" or "unsure" as to whether they had a care plan in place following their diagnosis. A small number of participants said they had a care plan with DCC and others said they had been linked to the DDSS.

Sample of comments:

- *"I believe a care plan was developed early on, but nothing has ever come of it"*
- *"We had a home visit from Making Space and the dementia advisor explained things around a care plan but I am unsure whether it has been developed or not".*

Review within first year of diagnosis:

Some participants were unable to provide an answer due to being recently diagnosed. Some participants talked about a yearly review, whilst others said that they had no review or update on their diagnosis at all.

A number of participants explained they were under the Community Mental Health Team (CMHT), doctor or consultant and felt their diagnosis was being monitored.

Sample of comments:

- “We have a review booked with the consultant, but this is 18 months after the diagnosis and there has been nothing in between”
- “We go every year for a review, but I think they are a waste of time as my wife can no longer read and she does not understand what is happening. It is not a pleasant experience for us”.

7.3: Supporting well

Support from Health and Social Care services:

There were mixed experiences of support following diagnosis. Some participants did not feel they needed support as they were “coping fine at the moment”. A number of participants explained they now have the support in place but it has taken a long time.

Some GPs were seen to be very supportive. A few participants were still under their consultants although as mentioned previously not all participants had regular appointments/reviews.

When asked if participants had a ‘named support worker’ the majority did not have one. Others talked about their dementia advisor (DA) from Making Space, their CPN, social worker or care co-ordinator.

Sample of comments:

- “We do now have the support in place but it has taken so long as I have had to do all the organising”
- “It has been a long, painful, emotional and stressful journey along the dementia pathway so far but we have been shown so much love and affection, it has been overwhelming”
- “It has felt like hard work; as a family we have had to be proactive in getting the information and the support we needed”
- “He (the GP) has been excellent and attentive and has been honest with us about my mum’s condition worsening”
- “We were put in touch with our care co-ordinator and she was marvellous”
- “We thought we had a named social worker, until we contacted them and we were told we had been discharged from the service as we had not been in contact for a while”

- “My friend has recently been diagnosed with breast cancer. All the support was put in place for her straight away, however when you are diagnosed with dementia, if you are seen to be managing and coping OK you don’t get any help at all”
- “People living with dementia are not always taken seriously. The system is not geared up for conditions such as dementia because you cannot see it. If my mum had cancer, the support would have been put in place for her”
- “There needs to be better communication between services. I have only recently been notified of the financial support and what is available to us and I feel I should have been notified sooner so I could have planned things better”.

Experience of hospital:

There were mixed experiences on hospital wards. One participant explained that dementia key workers are not available on all wards. Participants said that on the whole, once they had explained that their loved one had dementia the quality of care seemed to improve.

Many participants explained how crucially important it is for professionals to explain what they are doing.

Not all staff knew about ‘This is Me’:

https://www.alzheimers.org.uk/info/20033/publications_and_factsheets/680/this_is_me

Sample of comments:

- *“The staff are excellent on dementia-specific wards, but on others there is a lack of awareness and training so staff may think someone is being odd or aggressive when in fact, it is the dementia causing them to act this way”*
- *“My husband went into hospital with an injured leg. The staff were not aware that he had dementia or how to deal with him and I feel he was overlooked when he was trying to speak. I think it is important to remember that people with dementia can be anywhere within the hospital”*
- *“I have told all the departments that my husband has dementia and I noticed they became much more tolerant of his behaviour and mannerisms”*
- *“When I explained he had dementia it got a lot better, but I don’t know if I should keep having to tell them as it should be on his records”*
- *“The care was second to none, their dementia awareness was fantastic, and the staff spoke to my husband with dignity and respect and understood what he had said, even though he mumbles a lot”*
- *“We saw a consultant who was absolutely fantastic and explained everything to us which is so important for people with dementia”*
- *“I asked the staff about the ‘All About me’ document but the nurses had never heard of it and said they may just be on the older people’s wards”*
- *“They need to continue to improve awareness of dementia among staff”*
- *“For wards to become dementia-friendly, there is a lot of training available and it is excellent but people are so busy. Wards need to be more aware of the enhanced support teams and they need to use them at the right time”.*

Support at home:

Not all participants received support at home due to it not being needed currently. The participants who did receive support at home had mixed experiences depending on the provider. Participants who received care from DCC spoke highly of the care provided and commented around the 'high level of training'. However, it wasn't always available.

Our engagement officers were told some people do not qualify for DCC support, as their needs are not regarded as sufficiently critical. They also stated that when needs become more acute, people do not ask for a re-assessment, which means that people can find themselves in a critical state.

Participants who used private homecare services felt the carers were not always well trained, especially in terms of personal care. There were also concerns about the continuity of carers and flexibility around the timing of visits.

Sample of comments:

- "My mum was really used to the DCC carers; she was used to the routine and all the staff knew her and treated her with dignity and respect"
- "All of a sudden we were told the care would stop and we would need to have private carers" (DCC)
- "DCC have said we cannot use their carers"
- "Homecare staff should have proper training on dementia and how to treat people correctly"
- "Carers should turn up on time as it impacts on my wife's tablets and medication as I have to wait until they have been before she can have her food and this means she is taking her tablets at all different times of the day. If they came on time there could be a proper routine"
- "The service is not reliable, there is no continuity and PLWD need to have the same staff so they feel comfortable and relaxed and do not get distressed"
- "I would like to have the same few carers so my wife will get to recognise them and she will be calmer and happier when she is being changed"
- "With the consistency of care being so important for PLWD there needs to be a move towards upping the status of a caring role by providing opportunities to build a successful, well paid career rather than the revolving door job it currently appears to be. Dementia care is a specialised area. If you get it wrong, the person being cared for suffers and their quality of life diminishes. With the right sort of care, life can be so much better".

Link with occupational therapists and home adaptations:

Participants valued support offered by the OTs.

Some comments suggest waits for equipment to be installed following the assessment. We were told by a professional that there can often be delays in providing 'dementia-friendly' equipment such as coloured hand rails. The standard white equipment is readily available but orders have to be approved for customised equipment causing delays, therefore some people will just ask for standard equipment aids to help them at home.

Sample of comments:

- “An OT came to visit us. They did a very good job and we had a stair lift installed”
- “We had a number of people come to our home to see what aids and adaptations were needed. There was a lot of proactivity but we lost sight of it because of our daily battles”
- “We asked for handrails to be fitted to help dad move around the house, yet we are still waiting for them”
- “We asked for handrails three weeks ago and we are still waiting”.

Falls prevention:

We asked participants questions around reducing their risk of a fall. Their responses are shown in Fig. 1 below.

Participants who received information around reducing their risk of falls received the information predominantly through DCC, an OT or through the Living Well Programme.

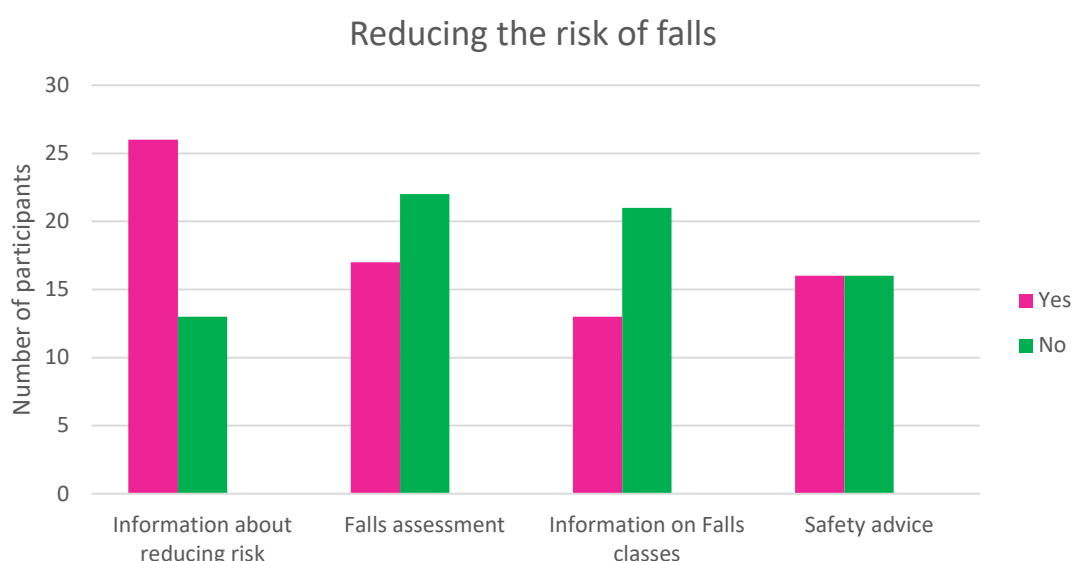
Some participants were still waiting for their falls assessment.

Falls classes were found to be beneficial, but not everyone could attend due to difficulty with travelling to them.

Sample of comments:

- *“It took a while. We contacted an OT for an assessment and five or six weeks had passed. We had not heard anything, so I chased them up and we were told we were 56th on the list”*
- *“Once I started them (falls classes) I have not looked back. They teach you how to get back up properly if you ever fall”.*

Fig. 1:



Safe and Well Checks (Derbyshire FRS):

Participants valued the advice and information received from the Derbyshire FRS, via safe and well checks.

Sample of comments:

- *"The visit from the Fire Service was helpful as I had new fire alarms fitted"*
- *"They put new fire alarms in our house. This was nice to have and it was reassuring"*
- *"The Fire Service have been excellent and have supported us with a number of our patients" (Professional).*

Support from day centres and independent groups:

Participants valued support offered by day centres and independent groups, such as church groups. Many participants explained day centres were a good place for their loved ones to go and participate in different activities and carers to receive respite.

A small number of participants commented around the fact that many groups and services provide support on the same days which in some cases causes people to have to choose.

A professional told EOs that workers are struggling to find activities for PLWD, and this has got worse in the last year.

Transport can also be a problem when it is not provided.

Sample of comments:

- *“Day centres for PLWD are great. It is great for them to stay involved in activities but it also gives the carers a break”*
- *“We have two things this week but then we have nothing for the rest of the month”*
- *Jubilee Centre in New Mills: “It is excellent; all the staff are supportive of both my husband and I. They have provided me with great advice and have been helpful throughout our journey”*
- *Still Waters in Buxton: “We love it and there is so much community spirit. We get support from each other and the atmosphere is great”*
- *Age UK: “Age UK are excellent” and “the day centre is excellent. We like doing all the activities - we like to dance, sing, cook and play games. The staff are lovely, we are always doing something different”*
- *Midway: “It is a homely environment and doesn’t feel like a hospital. They are wonderful and they make it as nice as they can for you”*
- *Stepping Stones: “I cannot speak highly enough of them. They are so supportive and they have a person-centred approach. We used to visit and it would be £10 which included a three-course meal and it was available 9:30-3pmish. Transport used to be arranged for us and we would go on days out. We once went to Scotland. I didn’t have to do anything whilst we were in Scotland; they did everything for us and if it all got too much for me they were there for me”*
- *Stepping Stones: Following a discussion with a professional, she said that “there is a gap in service as the Midway hospital now only runs a two-hour day service. It used to be from 9-3. However, people are now dropping out as it is no longer viable for carers as it does not give them sufficient respite. There is great need for day care as it ensures that full-time carers get at least some time to themselves once a week. The end result may be that more people end up going in to a crisis and people have to be put in care”.*

➤ **Derbyshire Dementia Support Service (DDSS):**

Transition to Making Space:

Many participants had been involved for many years with its predecessors.

Most participants commented around the transition to the new provider. Some felt that they had not had a say in the change of provider and felt the transition caused a lot of distress as it was not done so well.

There was a lack of continuity with the DAs and there were ever-changing timetables and a general lack of organisation.

Sample of comments:

- *“My mum has not coped well with the change and no longer engages at all”*
- *“My mum felt so uncomfortable and has asked that we do not go again”*

- *“When they first took over it was not good but [named worker] is superb. I do not feel they get the backup they need. For example, the training, they have just been placed in the deep end”.*

Training and knowledge of the dementia advisors (DAs):

A large proportion of participants felt the current DAs did not hold enough knowledge around dementia. In some instances, the DAs were not referring people onto other means of support such as Derbyshire Carers Association (DCA), Sight Support, or Strictly No Falling.

Sample of comments:

- *“They (DAs) lack the insight. They say they have had dementia training but I feel they have been thrown into the deep end with very little support”*
- *“[Named worker (DA)] tries their best but he does not really know what he is doing and I would not feel comfortable contacting him for support”*
- *“When the Herbert Protocol came out we asked the facilitator if she knew about it. She explained she had been to the inauguration but did not have any information or forms for us”*
- *“Staff should be trained so they are able to offer dementia advice”*
- *“[Named professional] cannot seem to answer specific problems we are having around my husband’s condition and we are just told to go to the GP for help”*
- *“It was so disorganised and the workers had little knowledge of working with people who have dementia”.*

Facilitation and quality of the groups:

The majority of participants felt that there was poor facilitation around activity sessions and support groups. Some activities such as bingo and quizzes were felt to be causing people to become upset and frustrated.

Participants explained they would prefer the groups to be a place of sharing information and learning about the support available, rather than social activities.

Some participants did speak positively of the groups and the experiences of the musical memory groups were mixed.

Sample of comments:

- *“We told them we would like to have a focus but they just wing it”*
- *“The group facilitator seemed ill-prepared for two hours with people living with dementia”*
- *“My husband no longer wants to go. He feels the sessions underline what he can no longer do”*
- *“Stop just having colouring; I am not a child”*
- *“Why have things from before I was born? Of course I will not remember them”*

- *"It is our first time at the group, we were not introduced and it was not made clear what the sessions were about. We were told it would be a place to get help but instead it was just playing games that we didn't understand nor did we finish"*
- *People do not all wish to be seen as the same. Some are happy and content to play bingo, and other games or discuss the 1940s. But others are highly professional retirees who have led lives that have never engaged in bingo. Maybe for this reason, some of the participants considered the sessions patronising and demeaning"*
- *"We want more than just games as we want to learn things that may help us"*
- *"They should be more proactive and provide meaningful activities for people to attend and get something from it"*
- *"More of a social rather than a source of direct meaningful support"*
- *"They are excellent (groups). It is a lovely atmosphere and it is very relaxed with no strict agenda"*
- *"My wife likes going to the group because it is for her and not her condition. I also feel very welcome when I go along too"*
- *"It was a disaster; the worker who was tasked with taking the group would turn up late, leaving everyone without anything to do or any drinks. This was not just one occasion, this was every time. Eventually, the church who hosted the room offered to take over and facilitate it. It is now absolutely excellent with a turnout of around 40-50 regular members"* (Musical Memories)
- *"They are really good"* (Musical Memories)
- *"It was a smooth transition. I think it helped because it was the same people running the group. We both enjoy attending and it is an enjoyable experience"*
- *"Making Space would not pay for a professional musician at a Musical Memories group. The song book they developed was too heavy for people to hold and had a large number of spelling mistakes in. There are a number of groups that have broken away and have started up on their own with support from local churches"* (Musical Memories/Professional).

Confusion caused by changes to timetables:

There seemed to be a lot of confusion caused with changes to dates and venues with some being inaccessible. Also, some of the groups were changed from fortnightly to monthly.

Sample of comments:

- *"There are more benefits to regular sessions; monthly sessions are just putting people back into social isolation"*
- *"The change of timings for the group is causing people to be unable to attend"*
- *"The changes in times and venues has been an ongoing issue for the past year with ever-changing timetables and umpteen versions being printed and distributed. This is incredibly confusing for members, especially when some cannot always attend every month and find the times have changed the next time they turn up. They then feel unwelcome and that they have disrupted a group if the group has already started".*

One-to-one support:

We were only able to gather one experience of a participant receiving one-to-one support. Participants in the main had received no meaningful one-to-one support, with quite a few participants explaining they had been ‘promised’ support which never happened.

Participants felt that they would have benefitted from one-to-one support, in terms of having a named person to go to for support but also, as a way of being effectively signposted to other services.

Sample of comments:

- *“The staff do not know enough about dementia to provide accurate help. I have had to find out about things through friends and neighbours”*
- *“There should be a one-stop shop rather than ringing around different organisations and remembering who to chase up all the time”*
- *“When I was diagnosed I was referred to Making Space and they have been superb. They have been very helpful in providing support when we have needed it”*
- *“Initially they were wonderful. They told us ‘we can do this and help you with that’ and we felt absolutely supported and then we never heard anything from them. I contacted them and we managed to get a home visit. Again we were promised everything and received nothing. They are a waste of space. We have had nothing but false promises and I have no confidence in Making Space at all”*
- *“My wife is newly diagnosed and we have said in the group that it would be really nice for someone to give us a phone call, but the workers just seem to talk to other staff during the group. They do not come around to us and ask how we are doing”*
- *“Where are the resources to train the staff in providing one-to-one support in key issues which makes all the difference between crisis and providing the safety net through the tough times?” (Professional)*
- *“There should be a triage system for when someone is diagnosed where they can contact and make referrals on your behalf based on your needs so it is personalised. Alternatively, the triage system could offer signposting as sometimes you do not know who to turn to for support due to there being so many organisations involved”.*

7.4: Living well:

Recognising the role of a carer and having an assessment:

Many of the participants spoke about how they now identified themselves as a carer for their loved one, but not all participants did.

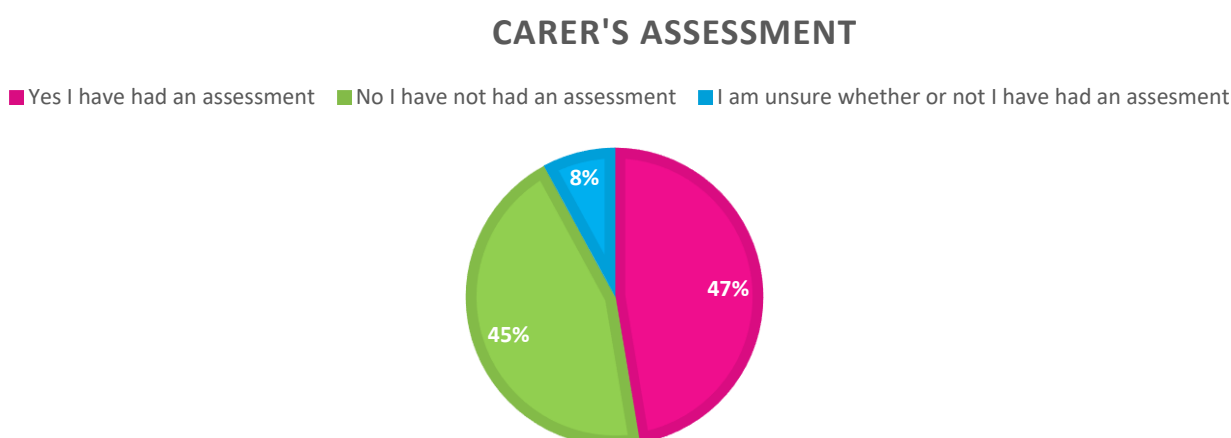
There were mixed reports from carers with regards to access to information following their loved one’s diagnosis.

Those who did identify themselves as a carer were asked if they had received a carer's assessment through DCA. This information is provided in Fig.2 below which demonstrates a mixed response.

Some participants didn't feel an assessment was needed or they could not see a benefit.

Some comments suggested a lack of communication with DCA.

Fig 2:



Sample of comments:

- *"My son explained to me how my role as a wife had now changed"*
- *"Yes, I am her carer, but she is my mum at the end of the day. She looked after me for 20 years so I am just returning the favour"*
- *"Yes, and I do everything for her and I want to carry on doing it for as long as I can. It is my job as her husband to look after her"*
- *"We are a couple and we support each other; that is what you do"*
- *"I had one (assessment) a while ago but I wanted to update it. I rang DCA to explain and was told someone would be in touch. A few weeks ago I contacted them again as I had not heard anything and I was told I was on their system but I have still not heard anything"*
- *"In the autumn of 2016 I had an assessment, however this was not finished and it did not lead to any further help. I had to do all the calling and arranging myself"*
- *"When I was waiting for the assessment to be done over the phone, I arranged for a befriender to sit with my husband whilst the assessment was taking place, but then DCA did not ring me back. It was very inconvenient as I had to arrange and change the time of when the befriender usually comes"*
- *"I can't even get through to them. I have tried to call them a number of times in the last year and no one has rung me back. Carers don't get called back and it is very vague as to what is on offer for them" (Professional).*

Registering as a carer with a GP:

Most participants had registered as a carer with their GP, however other participants were unsure as to whether they had officially registered as a carer but believed their surgery or named doctor was aware of their caring responsibilities.

Some participants who had registered as a carer spoke positively of the support received by their GP surgery, using words such as “flexible” and “supportive.”

Sample of comments:

- *“My GP is very sympathetic to my role as a carer”*
- *“The surgery have been very accommodating when I have needed appointments which fit around my role as a carer”*
- *“We have a carers champion in the practice and she makes sure that people have had a carer’s assessment and that they are aware of their rights” (Professional).*

Carer’s emergency card:

With regards to the carer’s emergency card, responses were mixed with some participants explaining that they had a card but hadn’t had to use it, and some said they were not aware of the card, but would have found it useful.

Sample of comments:

- *“I do not think there is enough emphasis put on emergency plans and not everyone has support around them”*
- *“This would have been useful. I was recently in A&E and I had no one to look after my husband so he had to come with me and sit there for seven hours. The staff were lovely but he was becoming very distressed”*
- *“I do feel alone at times and I worry about what would happen to my husband in an emergency”.*

Respite care:

Participants explained they were aware of how to access respite but not all needed it currently. Some described the “lengthy” and “complicated” process to access respite, and the need for carers to be very proactive. Once the support was in place the experiences were generally positive, but not all carers felt they received enough respite.

Sample of comments:

- *“I asked the care co-ordinator about respite and I was told about care homes. I didn’t want to put my husband in a home. I then found out after I had done some ringing around about a day centre and now my husband goes every Friday and he loves it”*
- *“I receive one week of respite per year, but apart from that I do not feel I receive enough support”*

- *"The only respite I have been offered is two weeks in a nursing home. All I want is an hour each week to get my head around things and this would mean I could carry on doing the things I need to do and not get overwhelmed"*
- *"I was unsuccessful in finding a befriender for my husband so I could no longer carry on with my art group and choir".*

Caring responsibilities having an impact on participants being able to care for themselves:

A number of participants felt that their caring responsibilities were having an impact on their own health due to difficulties accessing the relevant support. Others talked about feeling "unsupported" and "alone" when caring for a loved one.

A number of carers felt they had lost their identity due to their caring role and were no longer able to participate in activities they used to enjoy.

A number of participants from a group in South Derbyshire felt that it was important that carers received a free flu jab, explaining that "if we became ill it would have a big impact on the health and social care system so we should be allowed free flu jabs. Some surgeries in the area are very proactive and encourage carers of people with dementia to have a flu jab but others do not".

Sample of comments:

- *"My GP advised me to access support from a CPN for my husband whilst I was going through treatment. The CPN got in touch two weeks before my treatment was finished so for me it was too late, the moment had passed. It is no one's fault, it is just the system was too slow"*
- *"Unwillingly I am too proud to admit when I need help for my wife and I get frustrated as sometimes I have difficulties going for my own appointments as they do not fit around my caring responsibilities"*
- *"They keep telling carers to look after themselves but you just can't".*

Support for carers:

Many carers felt they just needed a little more help to get the right support in place, i.e. in terms of time and understanding. Carers felt they had to become proactive in order to get support.

Sample of comments:

- *"Yes, I had a lot of support from DCA; they are very helpful in supplying literature about carers groups and what is in the area to help"*
- *"I have had to find out everything for myself"*
- *"I had to sort it all out myself. I was given brochures which took a long time to go through. I eventually found someone who then came to our home three days a week; they were lovely and really helpful."*
- *"Whilst you cope you are left alone"*

- *“Family carers need emotional support. It is devastating walking alongside someone as they lose their independence and become increasingly reliant upon their carers for every aspect of living during every step of their distressingly slow demise”*
- *“It really takes a toll on me. It is emotionally and physically draining; no one really understands the extent we have to go through to make sure mum is OK”*
- *“There are more and more people living at home with dementia and as a carer I feel I was taken advantage of. It isn’t easy making phone calls and keeping in touch with services when you are caring for someone”*
- *“We are still people too, but all I am now is the person who looks after my husband 24/7. I am not me anymore; I do not count”*
- *“Let us understand the decision making. Give us the time we need and the support. Our worlds are being turned upside down. If we get upset or angry please forgive us and understand why we are feeling like we do. We are grieving now and then we will have to do it all over again when our loved one passes away”.*

Co-ordination of services to support carers:

Support for carers was described as disjointed. Carers asked for better co-ordinated services, and better communication, i.e. a central organisation that can be contacted for advice, signposting and referrals.

Many participants who were caring for a loved one felt that they had to be very proactive and become ‘experts’ to be able to carry out their caring responsibilities and often felt this was ‘overwhelming’ and ‘confusing’ due to receiving very little support from organisations.

Carers also felt it should be the role of professionals to keep in touch, and check out how they were doing, rather than the carers doing all the chasing. Participants felt there is a need for more peer support.

Sample of comments:

- *“Everything (services) seems disjointed and you are unsure of who to go to”*
- *“There should be a central organisation who you could contact for advice and referrals if required”*
- *“There should be a triage team where you can contact them for advice, signposting and referrals”*
- *“There are too many organisations which makes enquiries for help, lengthy and complicated so people are often left to fend for themselves”*
- *“They rely on people being forceful but not everyone is like this and people are struggling with everything. I don’t like the fact you have to ask for every bit of information or help when it should be offered”*
- *“My caring duties leave me little time or energy for organising and searching things out and during my occasional free time I need that to relax and recuperate”*
- *“Organisations should be more proactive (i.e. making contact with carers, calling to see how they are) which would take a bit of pressure away from carers”*

- *"I would like to have someone to talk to as I feel alone. I have to carry on for my husband as there is no one else to care for him. I would like to be able to talk to people who are going through the same situation on a one-to-one basis because professionals never have enough time to talk to us"*
- *"Peer support would have helped, being able to talk to someone who is going through the same as you and knows what to do. It would be good to set up a buddy system so that things are shared and you can have someone to talk to".*

Paying for care (self-funding):

Some participants who were self-funding explained their struggles of getting the advice on relevant care and support. Participants explained they had contacted the relevant agencies for support but as they were self-funded they were often just sent leaflets or brochures through the post with no further support.

Sample of comments:

- *"Just because we have money does not mean we know how to care for someone with dementia properly"*
- *"The moment they found out we had money, our case was closed within a week"*
- *"Left to fend for ourselves"*
- *"I needed to go for an appointment for my own health and the prices I was getting back were so expensive. The figures were ridiculous for a few hours. The appointment was for my own health; I was not going on a jolly"*
- *"There should be more support for self-funders as it is chaos and very frustrating"*
- *"I am happy to pay for day care but people on the phone do not know where to refer you. I have spent hours on the internet looking at what help is available to us"*
- *"If you have your own funding, you are on your own. If my husband had cancer he would have been treated under the NHS but with dementia they know there is no hope of you getting better"*
- *"It seems to me that because we were self-funding we were just left to get on with it, but with dementia there can be a rapid decline which can mean we need help and we need it now but I don't feel the system accounts for that"*
- *"It felt as though your mum has a carer, me, and you have money so you can manage on your own".*

Paying for care (Continuing Healthcare):

A number of participants expressed their concerns around understanding the CHC process, and difficulties accessing funding. There were also comments about jargon used at 'funding meetings' which made them feel unable to participate.

Sample of comments:

- *"It has taken me over four months to try and understand the CHC process. Professionals have made no effort to help me understand the process or to get funding that we are entitled to"*

- "It has been an absolute nightmare; it is a confusing process due to the lack of information and it is very easy to be fobbed off, so if you are not aware of the process you can easily miss out"
- In late 2017 one participant's husband was discharged from hospital on End of Life Care (EOL) and said that "they did not fast track him as they can only do this if they suspect EOL within six weeks so I had to pay the care costs and I did not get CHC until two days before he passed away"
- "The funding meetings are so important and cause so much stress to families. They should provide people with more information prior to the meetings so people are aware of how the process works and what to expect"
- "We are a strong family; we will challenge the NHS or Social Care but not everyone will. What would have happened to them?"
- "We were told we would be eligible for £530 per week but her care was around the £1000 mark. That would mean as a family we would need to fund £400 per week. How could we afford to continue to fund that, when she is still quite young? It was a very challenging time for the family"
- "We tried to challenge the decision but the social worker kept on saying 'you can get her nursing care for that price'. Yes, maybe we could, but we did not feel they were fit for purpose; she needed dementia and nursing care".

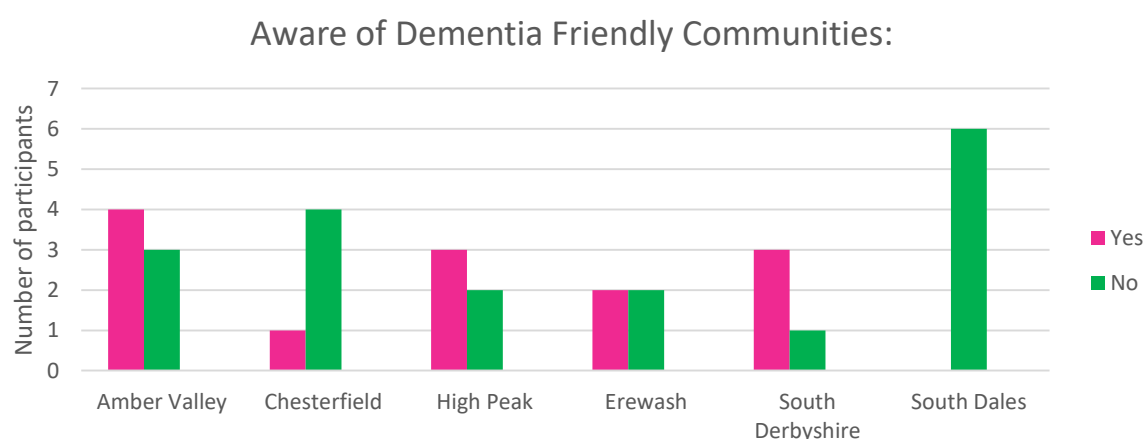
➤ Dementia Friendly Communities:

Aware of dementia-friendly communities:

We asked participants whether they were aware of Dementia Friendly Communities (DCF) and whether they thought Derbyshire was dementia-friendly. Some participants gave some suggestions for improvements.

The chart in Fig. 3 shows the responses for the people who answered this question.

Fig. 3:



Sample of comments:

- "It is getting better"

- *"They are doing what they can"*
- *"For people to have more of an understanding and to be patient; I do not want to shout 'this man has dementia', and when we go out for meals it can take him a long time to choose his food"*
- *"When we get a diagnosis it doesn't change who we are. We don't want to be treated any differently. We don't want people to start walking off the minute dementia is mentioned"*
- *"I would like shops to count out change. My husband gets very confused as he is just given a handful of change"*
- *"To have a leaflet on what dementia-friendly means. This way people would be more aware and we would be able to spot things"*
- *"To have dementia-friendly parking spaces; my husband does not qualify for a parking badge and I have to make sure I park somewhere where I can open the door wide enough for him to get out"*
- *"A friend has been to the airport and if you are with someone with dementia they give you a lanyard which makes people aware they have memory loss. I think this would be good if shopping centres and supermarkets could do something like this"*
- *"For supermarkets to have a dementia-friendly shopping session. I have heard they do this somewhere in the north of the county".*

Involvement in dementia-friendly projects and groups:

A small number of participants were involved with dementia-friendly projects and participants who attended dementia-friendly swimming or walking spoke very positively of them.

Sample of comments:

- *"It is brilliant; it enables the person with dementia to really open up about how they feel" (Amber Valley Discussion Group)*
- *"I love the swimming. I think the more I can do, the better I will stay" (Dementia Friendly Swimming)*
- *"The dementia-friendly swimming has been a boom to my husband. When he was first diagnosed I tried for ages to get him back in the pool. He was a beautiful swimmer but he just would not swim for me, then I heard of this and when he got back in that pool he took off. People here are lovely and it is great for us to meet new people and talk to other carers"*
- *"I go on the dementia walks which are good. You can just walk and talk together and it is really nice".*

Experiences of People Living with Dementia under the age of 65

7.5 Preventing well:

Education and consideration to images used:

As for the over 65s, many participants explained there needs to be a shift from the focus around Alzheimer's disease to awareness of all types of dementia.

Participants under 65 years old also felt the image used for dementia often portrays a "negative image" and can sometimes imply that dementia only affects older people.

Sample of comments:

- *"They always use images of older people who cannot eat or cannot do something for themselves. This is just portraying a negative image"*
- *"It would be better if there was a wider range of materials available so people are aware of other types of dementia and the symptoms to look out for"*
- *"If you are young you cannot get it recognised as dementia. My husband did not want to recognise it himself because when the word 'dementia' is used you automatically think of an older person, and they need to change their image".*

7.6 Diagnosing well:

Initial discussion with a professional:

When participants discussed their initial concerns with a GP, the experiences were mixed. Some participants felt their symptoms had been 'downplayed' and were told they are "too young to have dementia", whereas other participants had very positive experiences and felt listened to by their GP.

Sample of comments:

- *"The doctor was very sympathetic and understanding towards me and made a referral"*
- *"They were really good. They spent the time listening to me, they completed a questionnaire and then referred me to the MAS clinic"*
- *"They downplayed my symptoms and said that I will be fine in a week or so"*
- *"Not really, they kept on saying I was too young and then they put me on tablets for depression for around a year"*
- *"I wish I didn't have to keep on going back to my doctor before I got a referral just because I was too young"*
- *"No, we feel we have been left in a corner as my husband is younger. Lots of professionals have been in touch to say they will help but most of them we never heard from again".*

Information following diagnosis:

When asked if they had received adequate information following their diagnosis, participants explained the difficulty in accessing information around young-onset dementia and often did not receive the information required. Whereas, with the over 65s, some participants received 'too much' information.

Sample of comments:

- *"It is so difficult to get information around early onset"*
- *"After diagnosis you are told about different individuals that will be involved in your dementia journey but there are too many to remember. It would be good if once you are diagnosed, you received a one-page 'road map' that shows who is who and their role in your journey"*

7.7 Supporting well:

Support for young-onset:

Many participants felt unsupported and felt this was due to their age as there seemed to be a lack of support and activity sessions for younger people.

Participants explained the importance of recognising young-onset dementia and for the system to be able to provide meaningful and tailored support.

There was a discussion around the importance of 'understanding what dementia means'. As one participant said, "people do not understand what dementia means, there is no support available for people because it is an invisible disability".

All the members praised the DEEP groups and explained it allows them to be themselves and be with people who have some understanding.

Sample of comments:

- *"No, I feel we have had little support. After the Living Well programme nothing else was offered and the only support available is where people are of a much older age, for example, luncheon clubs. Workers seemed to give up as there was nothing for my age"*
- *"I am not something you put into a box - I am a person"*
- *"It has taken all my confidence away and I do not want to go out"*
- *"We tried a lunch club, but this is for very old and ill people and my husband felt very uncomfortable as he saw what he may become"*
- *"Not everyone wants a diagnosis but without the diagnosis there is no support"*
- *"Nothing is geared up for people my age. Nobody will talk to us or give us information and it makes me feel invisible"*
- *"I feel I am banging my head against a brick wall because the GP does not recognise what I am saying"*
- *"I feel like services have treated me like an idiot because I am young"*
- *"I feel people start talking to my mum when they find out I have dementia, just because I am young they don't know what to say to me"*
- *"It is like a family. [Named professional] helps me so much I am really grateful for the support" (DEEP Group).*

Improvement for people with early-onset dementia:

Following a number of discussions with participants with young-onset dementia, participants made some suggestions for improvements they would like to see in the future.

Summary of comments:

- *More support groups for younger people with dementia*
- *Improve nurses' attitudes, let people know that younger people can have dementia as well. One participant claimed that there was no dignity or respect for her husband as they just thought he was being awkward*
- *Personal health budgets to do age-appropriate things rather than quizzes and bingo*
- *Support for families of people with young-onset dementia, especially their children*
- *Increase employer's knowledge of accommodating someone with young-onset dementia in work*
- *Financial support, as often people with young-onset dementia are not entitled to a state pension, and have not saved enough in private pensions.*

Experiences of people living with dementia from the BME community:

7.6 Diagnosing well:

Receiving diagnosis:

Participants talked about the difficulty getting a diagnosis of dementia, taking up to two years for the formal diagnosis.

It was explained that some individuals are able to get a quicker diagnosis when family members can engage with services, however sometimes families can be in denial.

Sample of comments:

- *"People often resort back to their mother tongue when they have dementia and although interpreters are available, there can be a 'lack of trust' along with 'cultural differences' with interpreters which prevents access".*

7.7: Supporting well:

Support for participants from the BME community:

Participants felt there is also a "huge language barrier" with BME carers and PLWD in hospital settings. Participants felt it was important to have effective communication with PLWD as they can be often 'in denial' and will be 'complacent' with their answers.

It was discussed that homecare workers seem to lack general dementia awareness, which is also evident in numerous sections of the report.

It was discussed that individuals from the BME community need to have tailored support to meet their needs and one participant suggested having more befrienders from their local community.

Sample of comments:

- *“One of our members was in hospital and there was a huge language barrier and coupled with dementia it made it a very isolating place. The individual was then discharged late at night, returning to an empty house which caused more confusion”*
- *“We feel they need more training in communicating with people living with dementia. They ask questions such as ‘do you want a bath?’ to which they respond ‘no, I am OK’. This happens with a number of professionals; they do not probe enough”*
- *Participants also explained they often felt care was ‘rushed’ as they were only provided with 10-15 minutes of care, which was not enough time to support individuals effectively.*

8. What should happen now?

1. Continue to work to improve the provision of early education to raise awareness and understanding of dementia
2. Increase information and communication around all types of dementia and provide clear information on all signs and symptoms
3. Consider the images used for literature and campaigns to ensure the message is clear that dementia can affect anyone, regardless of age
4. Ensure initial concerns around suspected dementia are listened to:
 - Regardless of age
 - Consider the concerns expressed by carers and family members.
5. Work to reduce language barriers to ensure this does not delay diagnosis and to ensure people are fully supported throughout their journey
6. Consider and evaluate the amount of information provided following diagnosis, and to consider whether the information is delivered at the right time
7. Ensure there is opportunity for PLWD, carers and family members to ask questions following the diagnosis:
 - At a later date, rather than immediately after diagnosis
 - Ensure carers and family members are able to ask questions around their loved one’s diagnosis in private.
8. Work to ensure all PLWD, their carers and family members are signposted to appropriate support following diagnosis and ensure the support is easily available to access at a later date, if not required immediately after diagnosis
9. Promote the Living Well Programme and the question and answer sessions
10. Ensure the care and support needs of PLWD are met and regularly reviewed, as suggested in the Dementia Well Pathway

11. Ensure workers and professionals are able to identify patients/clients with dementia and their carers/family members and have received adequate training to be able to meet their care and support needs in all settings
12. Maximise the need and importance of continuity, routine and training for homecare staff
13. Improve the experience of people involved with the DDSS in terms of more appropriate activities, more training for staff and ensure the one-to-one support is readily available
14. Develop a role of a 'named person' to enable people to have one point of contact to be able to access the advice and support needed
15. Work to address the need for more support and activities for PLWD under the age of 65
16. To ensure carers receive the correct level of support to effectively care for their loved one and also look after their own health and well-being
17. Improve co-ordination of support services for carers, so they know where to go for advice, signposting and referrals
18. Ensure families who are self-funded have the correct level of information and support
19. Address the lengthy process for accessing respite care and to make it easier to access
20. Provide clear information around Continuing Healthcare and the use of jargon, so people are able to easily understand the process.

9. Response from service provider

The below table provides a summary of the responses received by service providers and commissioner's for the Healthwatch Derbyshire Dementia Report. The table has been produced due to the volume of responses received.

If you would like to view a full version of the responses please visit:

<https://healthwatchderbyshire.co.uk/wp-content/uploads/2018/05/HWD-DEMENTIA-REPORT-FULL-SERVICE-PROVIDER-RESPONSES.pdf>

Alternatively, you can request a hard copy by contacting us:

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Sustainable Transformation Partnership (STP):

NHS organisations and local councils have come together to develop plans for the future of health and social care. Derbyshire's STP, Joined Up Care Derbyshire, brings together work that has been taking place across the county to coordinate services better so they support people to stay well. For more information on Derbyshire's STP please visit:

<https://joinedupcarederbyshire.co.uk/>

What should happen now?	Response's:
1) Continue to work to improve the provision of early education to raise awareness and understanding of dementia.	<p><u>Sustainable Transformation Partnership - Dementia & Delirium Workstream:</u></p> <p>The STP has a key goal to minimise the risk of people developing dementia and delirium in dementia, and improving pre-diagnosis information and health promotion for prevention of dementia are important steps to this goal. Partners within the STP across the health and social care, and voluntary sector, have a stated commitment to improving the availability and quality of information for early education, awareness raising and the various types and manifestations of dementia. Partners also have a stated ambition to ensure their work is integrated to further support this, and other key STP goals. The STP, through the framework of operation, will monitor how this goal is</p>

	<p>progressed and achieved (This action also relate to recommendation 2 and 3).</p> <p><u>Derbyshire Clinical Commissioning Groups (CCGs):</u></p> <ul style="list-style-type: none"> - Specific sessions relating to ‘early recognition and early intervention of dementia’ were commissioned in Erewash in November 2017 (This also relates to recommendation 2) - Dementia Friends training is continuing across the county and many sessions are being offered as part of the Dementia Action Week (May 21st - 25th) - The CCGs are part of the local and county Dementia Action Alliances (DAAs) and are working on plans for dementia-friendly communities (DFC). Members of these alliances include retailers, banks, pharmacies, local MPs, and Councilor’s and local businesses. <p><u>Derbyshire County Council (DCC):</u></p> <p>One of the key commitments outlined in the DCC Council Plan is to develop support services for people living with dementia (PLWD) to help them live well and independently. DCC will continue to provide opportunities for its staff to attend awareness raising sessions to improve understanding of dementia.</p> <p><u>Chesterfield Royal Hospital NHS Foundation Trust (CRH):</u></p> <p>CRH aims to have an outstanding ‘dementia-friendly’ culture of care which will be achieved by ensuring that all Trust staff are dementia aware. The Trust will continue to run and promote an extensive portfolio of dementia training, which currently includes:</p> <ul style="list-style-type: none"> • Induction - all staff receive dementia awareness training at induction (also relates to recommendation 11) • Annual essential training - dementia awareness training for all staff (also relates to recommendation 11) • Care Certificate training - a nationally recognised qualification, including an agreed set of standards setting out the knowledge, skills and behaviours expected of Healthcare Assistants (HCAs) • Promoting Quality in Dementia - provides a better understanding of dementia and lived experience; this helps to equip staff in providing appropriate care and supporting people to live well with dementia - available for all staff • Best Practice in Dementia Care - in line with national dementia strategies, this programme helps organisations to achieve national and regional care standards. The
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	<p>programme is accredited by the Royal College of Nursing with 16 CPD hours and recognised by Skills for Care.</p> <p><u>Derby Teaching Hospitals NHS Foundation Trust (DTHFT):</u></p> <p>The Trust's dementia awareness training is now mandatory. Therefore, all staff starting in the Trust will receive the training as part of their induction. The training is also available to any existing staff who have not done the training since it went mandatory, via the one stop shops. The Lead Nurse for Dementia is also able to provide training to any areas where required.</p> <p><u>Derbyshire Community Health Services NHS Foundation Trust (DCHS):</u></p> <p>DCHS is developing a Dementia Strategy which will include the following key strategic objective: the continued development of our Trust as a dementia-friendly organisation, with environments that promote better outcomes, and that are safe.</p>
<p>2) Increase information and communication around all types of dementia and provide clear information on all signs and symptoms</p>	<p><u>Derbyshire CCGs:</u></p> <p>Dementia-friendly practices exist in some areas across the county (7 out of 12 in Erewash and 3 in the north). This continues to be rolled out but is a slow process.</p> <p><u>DCC:</u></p> <p>DCC will continue to improve and develop a range of information and signposting to improve pre-diagnosis information and health promotion for the prevention of dementia.</p> <p><u>Derbyshire Healthcare NHS Foundation Trust (DHCFT):</u></p> <p>At the point of diagnosis all patients are:</p> <ul style="list-style-type: none"> • Informed of their specific diagnosis and the rationale for why this is an appropriate diagnosis • Offered either face to face or referral to Making Space the Derbyshire Dementia Support Service (DDSS). They are commissioned to provide literature including information specific to their diagnosis • Offered the Living Well with Dementia education course that provides further education on types of dementia. <p>DHCFT will continue to:</p>

	<ul style="list-style-type: none"> • Work alongside DDSS staff in the diagnosis clinic • Provide information and access to the Living Well with Dementia education sessions • Promote Dementia Q and A sessions in different formats. <p><u>CRH:</u></p> <p>In addition to the above training (in recommendation 1), CRH has several avenues of support, where staff, patients and carers are able to seek further information:</p> <ul style="list-style-type: none"> • The Trust has established an Enhanced Nursing Support Team (ENST) to offer a gold standard of care. The ENST is a dedicated team of HCAs that provide a level of increased supervision to patients, including those with severe dementia. The team have received specific training and reside in a virtual ward managed by the Older People's Matron. This provides a flexible workforce with staff allocated on a shift by shift basis • A Trust Older Person's Team is available for support, advice and assessment • The Trust also has dementia information resources and packs available from Library Services • Dementia drop-in sessions are held every Tuesday afternoon and are currently run by Making Space - patients and carers are able to access information, advice and support about dementia • In January 2018, a Carers Liaison Officer came into post, who offers support, information and signposting to carers, and works with staff to ensure that they are able to provide this support • The Trust also has support from DHCFT Liaison Team. <p><u>DTHFT:</u></p> <p>The Lead Nurse for Dementia is currently organising a study day for staff in the Trust, around the different types of dementia, which will include looking at the signs and symptoms. This will help staff to feel confident to share the information with other staff members and carers. Staff can also signpost relatives, patients and carers to the information hub where there is information available around dementia. Information on types of dementia and signs and symptoms is to be provided via the dementia portal for all staff on the intranet. Enquiries are to be made to see if information around types of dementia and signs and symptoms can be put on the Trust web page for the public to view.</p>
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<p>3) Consider the images used for literature and campaigns to ensure the message is clear that dementia can affect anyone, regardless of age</p>	<p><u>Derbyshire CCGs:</u></p> <p>We are working closely with Making Space and Alzheimer’s UK who are supporting us with the production of literature for activities and events such as those taking place for Dementia Action Week in May. The current service provider, Making Space, has reviewed and reproduced its literature in light of these recommendations.</p> <p><u>DCC:</u></p> <ul style="list-style-type: none"> • DCC Public Health commission the Alzheimer’s Society to deliver the DFC project, highlighted in the report, that uses stakeholder engagement and awareness raising to empower people, businesses and organisations to become more dementia-friendly and help PLWD maintain their independence in the community • DCC has expanded its ‘Safe Places’ scheme to include those PLWD • The DDSS, provided by Making Space, plays a key role in disseminating information about all types of dementia, and DCC are working closely with Making Space to ensure the service reach is as wide as possible, including affected younger people • The Adult Care Information Service will review the leaflet and web page that it produced about dementia to take account of the point raised about the images used. We will also consider adding more information about younger onset dementia to our information set • The Carers in Derbyshire website (www.carersinderbyshire.org.uk/), which has been developed by DCC, will be reviewed to ensure there is sufficient information provided about younger onset dementia.
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	<p><u>CRH:</u></p> <p>A key part of Trust dementia training is to discuss the potential for patients under the age of 75 to have dementia, to equip staff with the knowledge and understanding that dementia can affect all ages. The Trust aims to be inclusive with all images used in publications including those regarding dementia. The Communications Team have been made aware of this recommendation and the Older Person's Team will ensure they liaise with this team when producing any future publications for dementia at the Trust.</p> <p><u>DTHFT:</u></p> <p>The study day organised by the Trust will include looking at early onset dementia. We will also look at resources and information around early onset dementia, available to both staff and the public in the information hub.</p>
<p>4) Ensure initial concerns around suspected dementia are listened to:</p> <ul style="list-style-type: none"> - Regardless of age - Consider the concerns expressed by carers and family members 	<p><u>Derbyshire CCGs:</u></p> <p>Awareness raising activities are taking place including:</p> <ul style="list-style-type: none"> • An individual with dementia and his wife providing a presentation at the Practice Managers Meeting in Erewash, to share their experiences in order to raise awareness • Dementia patient and carer stories being heard at the Governing Bodies of the CCGs to raise awareness of the lived experience • The findings of all the reports and other service concerns being fed back through services, for learning • The Memory Assessment Service (MAS) has been newly configured and decommissioned to have one MAS for the county and a MAS 24 service. The MAS at Ilkeston hospital underwent a quality review visit at the end of last year and was evaluated very well with a recommendation to gather patient and experience feedback going forward. <p><u>DCC:</u></p> <p>DCC adult care assessments are needs led and take into account any concerns regardless of age. DCC will continue to ensure that all services provided or commissioned by the Council are responsive to concerns expressed by carers.</p> <p><u>DHCFT:</u></p> <p>DHCFT provide training to GPs and the wider health community</p>

	<p>as requested. DHCFT will continue to respond to requests to provide dementia training at Quest events and to the wider health community.</p> <p><u>CRH:</u></p> <p>The Trust takes initial concerns around suspected dementia seriously and are able to listen to patients and carers via several avenues, including:</p> <ul style="list-style-type: none"> • Part of the Trust's Older Person's Team role is to find, assess and refer patients with dementia. All patients over the age of 75 will be assessed within 72 hours of admission to hospital. Those under 75 are assessed on referral from staff or self-referral • The Trust is establishing Dementia Champions, with the aim that every ward and clinical environment in the Trust will have a nominated champion to act as a link to the Trust developments in dementia, provide support and training to staff and work as a champion for excellence in care • The Carers Liaison Officer is able to offer one-to-one support, advice and signposting to carers • The Trust has signed up to John's Campaign, the principles of which recognise the valuable contribution of carers to the health and wellbeing of dementia patients • The Trust's Carers' Charter pledges that we will support the needs of carers, and work with them as partners in care. The Trust has developed a Carer's Passport to support this • 24/7 support is available from DHCFT's Liaison Team. <p><u>DTHFT:</u></p> <p>Dementia link nurse/champions meetings are being re-established, so we have lots of champions across the Trust who can address any concerns raised by families and carers.</p>
<p>5) Work to reduce language barriers to ensure this does not delay diagnosis and to ensure people are fully supported throughout their journey</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The STP workstream is in the process of developing an engagement strategy, and reducing the impact of language barriers and improving response to the needs of our BME communities across Derby and Derbyshire is key to that development. Health and social care partners are considering integrated ways of working they could deliver to reduce language barriers and improve support for people living with dementia. Progress will be monitored through STP framework at strategic, implementation and monitoring levels. (This action also relates to recommendation 4).</p>

	<p><u>Derbyshire CCGs:</u></p> <p>Provision of information in other languages is greater in the city and we will work across the county to look at this and assess need. With regards to communication generally, the dementia-friendly training covers general communication with people with suspected dementia and/or memory issues.</p> <p><u>DCC:</u></p> <p>The Council are working with key partners, in particular the BME forum to consider how to respond more proactively to the needs of BME communities across Derbyshire. All services provided or commissioned by DCC are required to facilitate access for those who may experience language barriers.</p> <p><u>DHCFT:</u></p> <p>There is no evidence to support the belief that BME patients are delayed in the process of diagnosis once referred to MAS. DHCFT provide Urdu and Punjabi dementia Q and A sessions and Living Well with Dementia Education Group. DHCFT will continue to promote the services in appropriate formats.</p> <p><u>CRH:</u></p> <p>The Trust has access to interpreting services to support communication with patients and carers.</p> <p><u>DTHFT:</u></p> <p>The Lead Dementia Nurse will ensure that staff are aware that interpreters can be booked for patients where there is a language barrier, when discussing a diagnosis of dementia and when attending appointments. We can also look at making sure that written information is available in various languages to reduce any language barriers.</p>
<p>6) Consider and evaluate the amount of information provided following diagnosis, and to consider whether the information is delivered at the right time</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>As the provision of information around preventing well develops, the volume of information useful at the point of diagnosis can be reviewed. As uptake of the Living Well Programme improves the volume of information provided at the point of diagnosis may also reduce. There is a stated commitment by health and social care partners to work in an integrated manner to deliver to the information needs of individuals, and to review the way in which this happens in an ongoing manner. The STP implementation group will provide a</p>

	<p>format to enable review and monitoring of progress. (This action also relates to recommendation 7).</p> <p><u>Derbyshire CCGs:</u></p> <p>Feedback from PLWD in Erewash identified the need for a local directory to support them/their family post diagnosis (This also relates to recommendation 8, 11 and 17). We are also working with Derbyshire Carers around the general level of information given to carers at assessment and throughout the journey, especially as circumstances change. This is to improve the timeliness of information. There is also a specific intention to look at the information and support given when circumstances change and people need to consider care and residential support, as this is often a time of pressure to make decisions in a short time period. Making Space are aware of this and work with their advisors to look at how they support this stage of the journey.</p> <p><u>DCC:</u></p> <p>In partnership with the NHS and others, DCC will review the information made available following diagnosis, to ensure people do not feel overwhelmed. The review has commenced and already identified that the DCC 'Guide to Dementia Services' leaflet should be provided at all MAS clinics.</p> <p><u>DHCFT:</u></p> <p>Information leaflets are provided by DDSS and the information is agreed with Commissioners.</p> <p><u>CRH:</u></p> <p>The Trust provides patients and carers with information regarding dementia that they are able to take away and read at their convenience. There are also trained staff members available to offer additional support, information and signposting to patients and carers as appropriate.</p> <p><u>DTHFT:</u></p> <p>Considerations and discussions to be made around what information is provided to patients and families following diagnosis, and whether this information is appropriate at the time of diagnosis.</p> <p><u>Making Space/Derbyshire Dementia Support Service (DDSS):</u></p>
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	<p>DDSS provide an option for support immediately following diagnosis at MAS across Derbyshire. Where information, guidance and support is requested at that time by a PLWD and/or carer, this is provided. In addition, the option is given for a one-to-one home visit from the same Dementia Advisor (DA). For anyone that wishes to receive support at a later date, the service information leaflet and contact details of the DA in attendance is provided. DDSS will review this process and establish whether a follow-up mechanism would be beneficial when the service is declined at this initial stage (this also relates to recommendation 7).</p>
<p>7) Ensure there is opportunity for PLWD, carers and family members to ask questions following the diagnosis:</p> <ul style="list-style-type: none"> - At a later date, rather than immediately after diagnosis - Ensure carers and family members are able to ask questions around their loved ones diagnosis in private 	<p><u>Derbyshire CCGs:</u></p> <p>This forms part of the MAS/diagnosis pathway, where individuals are offered attendance at specific Living Well sessions. There is also an intention to look at the contents of the Living Well sessions, as some people have said they would like a refresher or an update later on in the journey, or as needs change. The MAS has developed so that nurses can give the diagnosis, although this diagnosis will have been made by the consultant following a review of the assessments. This allows for greater time for the family and the patient to discuss the diagnosis and there are options for them to come back and see the nurse for more discussions at a later stage. There is also the option for them to arrange to see the consultant at a later stage, and telephone discussion and conversation with the team is also encouraged. Dementia Q and A sessions are also held at Ilkeston Community Hospital.</p> <p><u>DCC:</u></p> <p>Staff from the DDSS attend all MAS clinics to offer information and advice straight after diagnosis, or arrange an appointment at a later date. Private appointments are also offered to carers/ other family members. DCC are continuing to work closely with Making Space and DHCFT to ensure the offer of information/ advice following diagnosis is timely and proportionate.</p> <p><u>DHCFT:</u></p> <p>Dementia Q and A sessions are available. The Living Well with Dementia Education Group is offered to anyone diagnosed with dementia and their carer/ next of kin. DHCFT takes the clear view that the diagnosis belongs to the person diagnosed and it would be inappropriate to discuss a specific diagnosis without the person diagnosed being present.</p>

	<p><u>CRH:</u></p> <p>The Carers Liaison Officer, Older Person's Team, DHCFT Liaison Team, Carers' Champions and Dementia Champions are available to answer questions and provide further information whilst patients/carers are at the hospital, including one-to-one discussions. Trust staff will also signpost to support services in the community.</p> <p><u>DTHFT:</u></p> <p>We will look at what follow up appointments or resources are available to patients and families following diagnosis for any follow up questions after initial diagnosis. We need to ensure that patients and family members have an opportunity to ask questions independently and privately following diagnosis.</p>
<p>8) Work to ensure all PLWD, their carers and family members are signposted to appropriate support following diagnosis and ensure the support is easily available to access at a later date if not required immediately after diagnosis</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>Working to ensure all PLWD, their carers and family members are signposted to appropriate support following diagnosis and ensuring that support is easily available, is key to the activity of the STP workstream. Partners have a stated commitment to working in integrated ways to achieve this goal, not only within the bounds of what is available but also in seeking to advocate further for funding and services to support that aim. The STP strategy and implementation partnerships will be key to this activity.</p> <p><u>Derbyshire CCGs:</u></p> <p>The MAS has started to provide this level of signposting, with referral and signposting to the current service provider (Making Space).</p> <p><u>DCC:</u></p> <p>As part of the dementia workstream of the Derbyshire STP, we will work with partners to ensure signposting and support for PLWD, their carers and family members is timely, appropriate and accessible.</p> <p><u>CRH:</u></p> <p>The Carers Liaison Officer offers a follow-up phone call with carers two weeks following discharge of the PLWD to ensure their support needs have been picked up in the community. There is also a self-referral slip for Derbyshire Carers within Trust carer's packs. Trust staff are trained to recognise and identify carers both at induction and annual essential training.</p>

	<p>There are dementia and carer's links provided on the Trust web pages, which signpost to further support.</p> <p><u>DTHFT:</u></p> <p>We can provide all patients and relatives with a resource folder which contains lots of information around dementia and also signpost them to the various community groups who they would be able to get support from.</p> <p><u>DCHS:</u></p> <p>DCHS is developing a Dementia Strategy which will include the following key strategic objectives:</p> <ul style="list-style-type: none"> • Early specialist support for people who have been diagnosed with dementia • Targeted support (including cognitive stimulation and meaningful activity) to enable people with moderate dementia to continue to live well • Listening, involving and engaging with PLWD and their carers including the timely completion of dementia care plans • Ensuring prompt referrals to specialist services
<p>9) Promote the Living Well Programme and the Question and Answer Sessions</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The transformation of day hospital services is a key goal of the STP and within this there are changes planned to the way the Living Well group is offered, to improve take up. It is planned that individuals diagnosed with dementia will be contacted up to three times during the year following diagnosis to encourage take up of the programme. The STP key goal is to ensure that services available anywhere in Derby or Derbyshire are equitable and this transformation is planned for North and South services in partnership with the two Trusts who will deliver the service. It should be remembered that the Dementia Q and A sessions are run voluntarily by DHCFT staff, and although they work very hard to sustain the offer, it is not always available. Under the STP, partners have agreed to look at ways that this could become more sustainable as it is a valuable service.</p> <p><u>Derbyshire CCGs:</u></p> <p>This now forms part of the MAS/diagnosis pathway where individuals are offered attendance at specific Living Well sessions. We will work with DCC, DHCFT and DCHS to promote</p>

	<p>the Living Well Programme and Q and A sessions more proactively.</p> <p><u>DCC:</u></p> <p>DCC will work with DHCFT and DCHS to promote the Living Well Programme and Question and Answer sessions more proactively. Staff from the DDSS, commissioned by DCC, already attend both Living Well, and the Q & A sessions, and we will consider options to integrate the service even more closely.</p> <p><u>DHCFT:</u></p> <p>DCHFT run the Dementia Q and A sessions in the South. They are due to recommence in the North (10/18). The Living Well with Dementia Group is provided by DHCFT in the South and is offered to all people newly diagnosed.</p> <p><u>CRH:</u></p> <p>The Trust:</p> <ul style="list-style-type: none"> • Will continue to work closely with DHCFT Liaison Team, who would refer into the Living Well Programme on behalf of the Trust, at diagnosis • Has two GP practices as part of its portfolio of services, which include mental health practitioners and GPs, who are able to refer into the programme. The Carers Liaison Officer is due to undertake Carers Awareness training with GP staff, and GP Carers' Champions will be launched in June 2018 • Will work to actively promote the Living Well Programme in both primary and secondary care settings <p><u>DTHFT:</u></p> <p>Ensure that information around the living well programme is given to patients and carers on diagnosis and that information is also in the resource folder and on notice boards.</p>
<p>10) Ensure the care and support needs of PLWD are met and regularly reviewed, as suggested in the Dementia Well Pathway</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The overarching key aims of the Derbyshire STP workstream for dementia and delirium are defined under the Dementia Well Pathway and there is a stated commitment by partners to ensure the needs of people with dementia are met and reviewed. The Strategy and Implementation partnerships will monitor this.</p>

	<p><u>DCC:</u></p> <p>DCC has adopted the Dementia Well Pathway as its framework for commissioning services for PLWD and their carers. This includes a commitment that all commissioned services will review needs regularly throughout the different stages of the pathway.</p> <p><u>CRH:</u></p> <p>The Trust undertakes a continuous patient experience survey to understand the experience of PLWD who use Trust services. In addition, friends and family feedback, concerns and complaints are regularly reviewed to identify any areas of good practice and opportunities for improvement.</p> <p><u>DTHFT:</u></p> <p>Support will be provided to the dementia key workers and dementia champions in the trust to ensure they can support all staff to ensure that the needs of PLWD are met and reviewed as required.</p>
11) Ensure workers and professionals are able to identify patients/clients with dementia and their carers/family members, and have received adequate training to be able to meet their care and support needs in all settings	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The Delirium partnership within the STP workstream is currently working to produce a low or no cost training package around dementia and delirium for roll out across all partnership members to try and enable better awareness and response for PLWD, to prevent and manage this dangerous condition that PLWD are highly vulnerable to.</p> <p><u>Derbyshire CCGs:</u></p> <p>Encourage uptake of the DCC awareness sessions across Derbyshire.</p> <p><u>DCC:</u></p> <p>DCC welcome the positive feedback within the report regarding the Council's own homecare staff support. DCC offers a specialist dementia training programme for care staff in addition to Care Certificate training, to ensure they work to the highest standards.</p> <p><u>CRH:</u></p> <p>The Carers Liaison Officer provides Carer Awareness training to staff. Champions will also be available to identify and support patients with dementia and their carers. Each carer seen by the</p>

	<p>Carers Liaison Officer is offered an application for a carer's emergency card. Staff are currently being educated on the recognition and utilization of these cards, particularly in the Emergency Department (ED). The Older Person's Team is in the process of establishing digital identification of patients with dementia, via the Trust's electronic patient systems. Bed head magnets have also been ordered to assist visual identification of patients with dementia at the bedside.</p> <p><u>DTHFT:</u></p> <p>All staff working on the care of the elderly wards with patients with dementia are to receive tier two training, which will ensure they are able to meet the needs of patients with dementia.</p> <p><u>DCHS:</u></p> <p>DCHS is developing a Dementia Strategy which will include the following key strategic objective:</p> <ul style="list-style-type: none"> • Comprehensive education and training for all clinical staff.
12) Maximise the need and importance of continuity, routine and training for homecare staff	<p><u>DCC:</u></p> <ul style="list-style-type: none"> • DCC is developing and expanding the Dementia Reablement Service, a short term specialist homecare service with a focus on continuity, routine and flexibility to help stabilise support at home • DCC aim to integrate the Dementia Reablement Service closely with the new NHS Dementia Rapid Response Teams, and share resources and training where possible • In May 2018 DCC will be holding a Best Practice in Dementia Care Conference, targeted at health and social care professionals, to enable further reflection and skill sharing when working with PLWD • The Carer's Information, Advice and Support service provided by DCA now offers training and learning opportunities for carers, based on what carers have told us they would benefit from.
13) Improve the experience of people involved with the DDSS in terms of more appropriate activities, more training for staff and ensure the one to one	<p><u>Derbyshire CCGs and DCC:</u></p> <p>Derbyshire County Council and the NHS Derbyshire CCGs are in the process of re-procuring the DDSS. This will provide an opportunity to review and clarify the service priorities which include a high level of training for staff, a range of appropriate activity/peer support groups and accessible one to one support.</p>

<p>support is readily available</p>	<p><u>Making Space/DDSS:</u></p> <ul style="list-style-type: none"> • Appropriate activities: Participants within all groups are encouraged to provide feedback following each session. This feedback is used to determine how future groups are planned, delivered and developed. Given the diversity of each group it can prove challenging to deliver sessions that are agreeable to everyone. DDSS make every effort to ensure that activity schedules are varied and appealing to participants. • Training for staff: Many of the DDSS Dementia Advisors (DA's) possess a wealth of knowledge amassed throughout long careers within a health and social care setting. For those less experienced there is regular, structured training aimed at improving and enhancing their knowledge base. All DAs have received dementia training from the Dementia Development Coordinator and Admiral Nurse Consultant for Making Space. There is a continual training structure in place covering a range of topics including: Person Centered Care, Distress Behaviour and Activity and Engagement. Although trained and knowledgeable, given the broad complexities surrounding dementia, there will be occasions where a DA will be required to carry out research in response to certain questions or requests for information. DAs will continue to receive regular training in order to maintain and develop knowledge and expertise. A package of training is being developed for the DDSS DAs by Stirling University, home of the Dementia Services Development Centre. This will be made available within the coming months. • One-to-one support: DDSS have conducted almost 600 one-to-one support meetings with PLWD and their carers since October 2017. DDSS provides a service for anyone that wishes to receive one-to-one support from a DA. This applies to anyone that is new to the service and all existing service users, including those attending groups. DDSS will ensure that all group participants are aware of the option to receive one-to-one support outside of group settings. As part of a package of support developed during one-to-one meetings, referrals are made to other partner organisations including Derbyshire Carers Association to ensure that identified needs are met.
<p>14) Develop a role of a 'Named Person' to enable people to have one point of contact to be able to</p>	<p><u>Derbyshire CCGs:</u></p> <p>There are different models across the county, for example in Erewash the Community Connectors act as referrers and introducers to services as do the Local Area Coordinators in the City and the North.</p>

<p>access the needed advice and support</p>	<p><u>DCC:</u></p> <p>DCC will continue working with the service provider (Making Space) to ensure that all clients accessing the service have the contact details for a named worker.</p> <p><u>CRH:</u></p> <p>In our Primary Care Settings, the named person to enable people to have one point of contact to be able to access the advice and support needed would be the Care Coordinator. Within the Trust, advice and support is provided by the Enhanced Support, Older Person's and DHCFT Liaison Teams; the Carers Liaison Officer acts as the named person for carers.</p> <p><u>DTHFT:</u></p> <p>The trust has a Dementia Lead Nurse who patients and relatives can be signposted to for advice and support.</p> <p><u>Making Space/DDSS:</u></p> <p>Upon referral to the DDSS a DA is allocated. This is determined by geographical location. This DA remains the single point of contact for a PLWD and their carer throughout their journey of support, and remains as such until all identified needs have been addressed. DDSS ensure that this is clearly communicated to anyone who is referred to the service, and that the relevant contact details are provided.</p>
<p>15) Work to address the need for more support and activities for PLWD under the age of 65</p> <p>(The responses to this recommendation also includes work/actions to provide more support and activities for people of all ages).</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The STP will review key deliverables to make more explicit the commitment to people of all ages with dementia, and work within the implementation partnership to support partners in services designed for people below 65 years.</p> <p><u>Derbyshire CCGs:</u></p> <p>Through the Living Well Sessions. As part of the Derbyshire STP Dementia workstream DCC and other key partners are reviewing service access and support available for PLWD under the age of 65.</p> <p><u>DCC:</u></p>

	<p>Service user review panel groups, set up as part of the DFC project consider the need for a more diverse support and activity offer, linking with local DAAs in some areas of the county to facilitate new activities such as dementia-friendly swimming.</p> <p><u>CRH:</u></p> <p>Funding has recently been agreed for an activity room and Activity Coordinator, which will be available to all patients of all ages.</p> <p><u>DTHFT:</u></p> <p>The Trust has a link to the national dementia support manager for early onset dementia, who is able to offer support and advice to patients, carers and staff around early onset dementia. I will be meeting with the lead to discuss what activities are available for these patients to support them whilst an inpatient. We currently have numerous memory boxes that staff can utilise to provide distraction as well as use as activities for our patients. We also have resources we can use as activities which include using apps to listen to music, watch movies amongst various other activities.</p> <p><u>DCHS:</u></p> <p>DCHS is developing a Dementia Strategy which will include the following key strategic objective:</p> <ul style="list-style-type: none"> • Promotion of activities that improve the wellbeing of PLWD and their carers i.e. activities that promote physical and mental wellbeing, applicable to the services that we provide to PLWD.
<p>16) To ensure carers receive the correct level of support to effectively care for their loved one and also look after their own health and well-being</p>	<p><u>STP Dementia & Delirium Workstream:</u></p> <p>The STP fully recognises the importance of the carer, the carer's needs and the carer's own health as being key to the person with dementia and their health and well-being, and the STP partnership will work to support the integrated ways of working, including working with carer's advocates and groups to ensure appropriate responses to the needs of carers (This action also relates to recommendations 17, 18 and 19).</p> <p><u>Derbyshire CCGs:</u></p> <p>We have been working with Derbyshire Carers regarding the feedback we had around carer's assessment and support provision. The responsibility for this contract does sit with</p>






	<p>Derby City Council but Derbyshire Carers have taken up our offer for Person Centered Care training which helps them to have conversations focused on the carer's needs and assets and their own wellbeing. Across the county there are also many discretionary voluntary and community groups and services funded to support carers. This includes day-to-day support for carers to go out, and also a carer's retreat facility in Derby City - Haven House.</p> <p><u>DCC:</u></p> <p>Ensuring carers in Derbyshire have access to the support, advice and information to best meet their needs is one of the priorities outlined in the Council Plan. Therefore we will continue to ensure that services respond proactively to supporting carers. DCC has involved carers in co-producing services including the DDSS and Dementia Reablement Service and will continue to involve carers where possible.</p> <p><u>CRH:</u></p> <p>The Carers Liaison Officer is keen to ensure that the health and wellbeing of carers is supported within the role. The Carers Liaison Officer is able to offer one-to-one support and advice, as well as signposting to additional and future support services as appropriate, as are Carers Champions. The Carers Liaison Officer will continue to work with carers for up to two weeks after patient discharge; they will be referred to Derbyshire Carers after this time, should they require further support.</p> <p><u>DTHFT:</u></p> <p>All carers have access to John's campaign room if they chose to stay with their loved ones, so they are able to take a break if needed. The facilities on offer are for carers to be able to access to sleeping facilities as well as kitchen facilities.</p> <p><u>Derbyshire Carers Association (DCA):</u></p> <ul style="list-style-type: none"> • Some of this is the core approach with groups to get carers to focus on their needs as they often are so focused on the cared for. Keep healthy related topics are being introduced more into some of the support sessions, also looking at other areas in the country to see whether different models could be developed which offer carers specific keep healthy sessions, this will require joint working with health providers which may need commissioner support
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	<ul style="list-style-type: none"> • Also commencing conversations with public health to see how the proposed PH hub model could also promote carer's health • Carer's emergency card is an area which definitely needs more work and clarification about what it can and cannot do and what the expectations are from a carer's view as well as the system. There is a lot of learning from the work so far especially in relation to how you can keep the info up to date, there is also the potential to link to the Summary Care record if commissioners can facilitate this so that Emergency Services and acute have a consistent approach.
<p>17) Improve co-ordination of support services for carers, so they know where to go for advice, signposting and referrals</p>	<p><u>Derbyshire CCGs and DCC:</u></p> <p>As part of the Derbyshire STP Dementia workstream, DCC and other key partners will co-ordinate and integrate support services so they are more accessible and help to build carer's confidence and resilience... A range of providers are working together within the Derbyshire STP Dementia workstream to identify opportunities for further co-ordination and integration of services. The views of carers are particularly important as many PLWD are not able to express their views.</p> <p><u>CRH:</u></p> <p>The Trust Carers Liaison Officer has established links with carers support services locally. The Trust's Carers Working Group includes representation from Derbyshire Carers and other local agencies, as well as carer representatives.</p> <p><u>DTHFT:</u></p> <p>We have a dementia resource folder for families who require information and advice, which signposts them to various community groups where they are able to get advice and support.</p> <p><u>DCA:</u></p> <ul style="list-style-type: none"> • We have become aware of these comments from carers and have in response looked at developing better joint working agreements/arrangements with our vol sector partners, especially Making Space. We feel this has the potential to be developed further, care needs to be taken not to duplicate or lose specialist knowledge • DCA have now increased links with the Living Well Programme and with care co-ordinators • There has been the promotion of the Carers in Derbyshire website, and DCA are improving their web site over the next 6 months

	<ul style="list-style-type: none"> Over the next year there will be the development of the carer connect hubs In relation to carer's assessment's - Staff have had more training both in assessment and person centred approaches - this has taken place over the last 4 months. <p><u>DCHS:</u></p> <p>DCHS is developing a Dementia Strategy which will include the following key strategic objectives:</p> <ul style="list-style-type: none"> Development of a Carer Strategy which will support the carers and friends of PLWD. This will include carer assessments, advice and advocacy support Development of partnerships to improve collaborative working and improve integration of care. This will address the concerns raised in the report regarding the disjointed nature of services.
18) Ensure families who are self-funded have correct level of information and support	<p><u>DCC:</u></p> <p>DCC continues to develop the Adult Care information offer for those who self-fund their care and support in line with the Care Act (2014). The Carers in Derbyshire website offers a range of vital information for self-funding families and we are committed to ensuring this information is accurate, up to date and relevant for self-funders.</p> <p><u>CRH:</u></p> <p>The Trust's discharge team liaise with Social Services who will then visit patients and discuss their requirements. The Carers Liaison Officer is also able to support carers in finding information and support (this also relates to recommendation 20).</p> <p><u>DTHFT:</u></p> <p>We can signpost people to the relevant service (Making Spaces) who will be able to provide information and support to families.</p>
19) Address the lengthy process for accessing respite care and to make it easier to access	<p><u>DCC:</u></p> <p>DCC will review the information it provides regarding how to access respite care, to ensure this is accurate, up-to-date and easily accessible.</p> <p><u>DTHFT:</u></p> <p>The Lead Dementia Nurse has arranged a meeting with the</p>

	Discharge Lead in the Trust to discuss the process around people accessing respite care.
20) Provide clear information around Continuing Healthcare (CHC) and the use of jargon, so people are able to easily understand the process.	<p><u>Derbyshire CCGs:</u></p> <p>The CCGs have revised their website information on this. We are working with DCC, STP and other providers to ensure there is a targeted approach to ensure carers supporting those in receipt of fully funded CHC are proactively identified and supported to access the carer's service.</p> <p><u>DCC:</u></p> <p>DCC will continue to signpost people to free and independent advice such as that provided by Beacon (http://www.beaconchc.co.uk/ 0345 548 0300) regarding the Continuing Healthcare process.</p> <p><u>CRH:</u></p> <p>The Trust is keen that patients and carers understand the discharge process and utilises the 'Red to Green' process, which keeps patients and carers informed of what needs to happen prior to discharge.</p> <p><u>DTHFT:</u></p> <p>The Lead Dementia Nurse has arranged a meeting with the Discharge Lead in the Trust to discuss information around continuing health care to ensure that anyone needing to access it is understandable, and that jargon is at a minimum.</p>

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p> <p>"I was given information about reducing my personal risk of getting dementia"</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p> <p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p> <p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	 <p>People with dementia can live normally in safe and accepting communities</p> <p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	 <p>People living with dementia die with dignity in the place of their choosing</p> <p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁶⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ BPSD ⁽⁵⁾⁽²⁾ Liaison ⁽²⁾ Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
References: (1) NICE Guideline, (2) NICE Quality Standard 2010, (3) NICE Quality Standard 2013, (4) NICE Pathway, (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway, (6) BPSD – Behavioural and Psychological Symptoms of dementia.				
RESEARCHING WELL <ul style="list-style-type: none"> Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change. Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries. 				
INTEGRATING WELL <ul style="list-style-type: none"> Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care. 				
COMMISSIONING WELL <ul style="list-style-type: none"> Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice. Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources. 				
TRAINING WELL <ul style="list-style-type: none"> Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community. Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes. 				
MONITORING WELL <ul style="list-style-type: none"> Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each. Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation. 				

11. Your feedback

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

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3) Since reading this report:

a) We have already made the following changes:

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b) We will be making the following changes:

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Your name:

Organisation:

Email:

Tel No:

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire DE56 0RN.