

# West and South Yorkshire and Bassetlaw Commissioning Support Unit



**Leeds North  
Clinical Commissioning Group**



## Living with Dementia: Engagement Report Leeds North CCG

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# Contents

<b>1. Introduction</b>	<b>3</b>
<b>2. Background</b>	<b>3</b>
<b>3. Engagement</b>	<b>3-4</b>
<b>4. Summary of Findings</b>	<b>4-5</b>
<b>5. Findings</b>	<b>5- 8</b>
<b>6. Conclusion</b>	<b>8</b>
<b>Appendix 1</b>	<b>Survey</b>
<b>Appendix 2</b>	<b>Organisations visited</b>
<b>Appendix 3</b>	<b>Focus Groups Notes</b>
<b>Appendix 4 -5</b>	<b>Equality data</b>



## 1. Introduction:

NHS Leeds North CCG is leading a city wide initiative to improve dementia diagnosis and post diagnosis support. To ensure the proposed redesign of the pathway meets the needs of patients and carers in Leeds a further consultation was undertaken to gain further insight from carers and people living with dementia; and to better understand any potential impact, whether positive or negative, that the proposed changes might have.

## 2. Background

As part of the review of the Leeds 'Dementia pathway' Leeds North CCG commissioned an engagement project: 'Dementia in Leeds: Evaluation Project 2013 by Leeds University. This evaluation included 47 interviews with people with dementia and or family members alongside general practitioner and worker perspectives. Additional feedback on the evaluation was provided by a small group of carers and people living with dementia supported by the Engagement team (WYSBCSU) and Leeds Involving People (LIP).

The review of the dementia pathway resulted in the proposed new model for assessment of memory problems, diagnosis of dementia, and post-diagnosis follow-up in Leeds. It aims to improve patient and carer experience and quality of care by:

- ensuring management of dementia is more joined up and patients and carers are supported more effectively;
- centring dementia diagnosis and post-diagnosis management around GP practices, enabling dementia to be managed alongside other health conditions and providing care closer to home;
- supporting GPs and practice staff by the outreach of secondary care clinicians; and
- it is proposed to invest in new staff roles, known as "Eldercare Facilitators", to support people through diagnosis and ensure people have information and support afterwards.

## 3. Engagement:

The Engagement team developed a comprehensive engagement plan, stakeholder analysis and survey.

### 3.1 Survey:

The survey was developed based on the proposed redesign and gaining an understanding of its potential impact on people living with dementia and their carers. To ensure it was accessible and easy to use the survey was previewed by carers and people living with dementia and adapted to better meet their needs. (Appendix 1)

LIP was then asked to undertake the response collection process with carers and people living with dementia from March to early May. The feedback LIP provided has been incorporated within this report.



### 3.2 Interviewing, Focus groups, Survey Completion:

LIP worked with the Alzheimer's Society which runs dementia tea cafes, support groups and singing groups throughout Leeds. They left consent forms for people living with dementia and carers to complete if they were willing to undertake the survey over the phone. Other dementia and dementia carer support groups were also contacted for survey completion (Appendix 2). They either completed the surveys face-to-face, over the phone, or in focus groups (Appendix 3)

#### Responses:

A total of 81 people were engaged with: 63 were people who care for someone who has dementia and 18 were people who have dementia.

#### Response Method:

61 surveys were completed: 47 by people who care for someone who has dementia and 14 by people with dementia

3 focus groups were conducted involving a total of 20 people: 16 of whom cared for someone who has dementia and four people had dementia.

#### Equality Monitoring:

Equality monitoring information for carers can be found in Appendix 4 and for people with dementia in Appendix 5. It should be noted that the predominant age range for all respondents was over 45 with no one under 35 involved, the majority of respondents were White British and there were no respondents from the Lesbian Gay Bisexual and Transgender community.

### 4. Summary of Findings:

- **GP first point of contact about memory problems:** respondents agreed with this because of the familiarity of the GP Surgery and were unfamiliar with any other option. There were reservations about GPs having sufficient expertise in dementia diagnosis and concerns regarding waiting times for appointments.
- **CT scans should become the usual procedure at the initial stage of diagnosis:** respondents agreed with this because they felt scans were very useful in identifying types of dementia, and other illnesses. However, further discussion was also needed about the condition following the scan.
- **Implementation of a support worker, once someone has been diagnosed with dementia:** The concept of someone who could offer support within the home was positive for both carers and those who have dementia with little or no concern raised about whether support worker was a qualified health professional or not.
- **Continuity of care:** was considered very important by all participants particularly for people with memory loss.



- **Options for services in the home were important:** as they recognised the need for support for carers and additional difficulties associated with leaving the home for people who have dementia.
- **Respondents expressed a preference for seeing specialists in the home or in the GP Surgery:** They were particularly in favour of home visits although the familiarity of the GP Surgery was also considered a good option. However there was concern about lack of privacy at a GP Surgery, people they knew might see them there and realise they had memory problems.
- **Medication reviews being carried out in GP Surgeries by GPs and/or practice nurses:** respondents were positive about this but were concerned about their GPs medical expertise about dementia.
- **Cognitive Stimulation Therapy service:** Those who had dementia felt it would be good to try something new. Carers felt that it would not only be good for the person that they care for, but it would also give them a break.
- **'Eldercare facilitator' name needs changing:** respondents preferred 'memory support worker', or just 'support worker'.
- **Respondents felt well supported, particularly by the Alzheimer's Society, Maicare and Carers Leeds.**

## 5. Survey Findings:

- 1) **In the new plan, your GP would remain as the first point of contact for concerns about memory problems, and carry out initial blood tests (a short memory test and some blood tests). Do you think this is the right approach, or should we make some more changes?**

**People living with Dementia:** All 18 of the respondents said that this was the right approach because of the familiarity of the GP Surgery which is an important factor for people with memory loss and they were unfamiliar with any other option.

**Carers:** 76% of the survey respondents said that this was the right approach. Those that left additional comments said that they didn't know where else you could go, that the GP is less intimidating than a Psychiatrist and even though the GP isn't an expert in dementia, they can refer to a specialist. The remaining respondents who weren't so confident about the approach said that this was because they were either unsure of the GP's dementia knowledge or had a bad experience in the past. This was because they had to push for a diagnosis or were concerned about the waiting time to get an appointment.

- 2) **At the moment, some GPs refer for a scan (CT head scan) at this initial stage. This will now become the usual procedure, unless you've had a scan recently or there is a good individual reason not to refer. Scans occasionally detect other illnesses that cause memory problems and can help diagnose the type of dementia. We want to make referral for scans more consistent, what are your thoughts? (Please explain your answer)**

**People living with dementia:** All the respondents said that this was the right approach. However, the participants in the Shakti focus group said that the scan must be followed up. One participant shared her experience of not having any follow-up from her scan about her actual condition, just being told that she couldn't drive anymore. She said that the scan shouldn't be all that GPs rely on for diagnosis



and they should also talk to the patient about how they are feeling. She also felt that the GP didn't understand her properly, as she was told that there wasn't any medication available to her.

**Carers:** 93% of the survey respondents felt that this was a good idea. Those that left further comments said that this was because it is important to know what type of dementia it is, so the most appropriate medication can be prescribed as quickly as possible. The remaining respondents said that they would still want to speak to a specialist, as they aren't that confident about the accuracy of scans and think that in depth discussion is needed.

**3) The next step for diagnosis and support is for the GP to make a referral to the memory service. In the new plan, patients and their families would receive a visit at home from a support worker. They would listen to concerns, gather initial information, and offer reassurance and support. The support worker role will not be a qualified medical person, but would refer to a memory nurse or other medical professional if required. Do you think this is would be helpful or not? (Please explain your answer)**

**People living with dementia:** All but one respondent said that this would be a good idea, as they would appreciate the support in their home. The respondent who didn't think it was a good idea said that they felt it was just another "cost cutting exercise" but did not explain further.

**Carers:** 93% of the survey respondents said that this would be helpful as they would appreciate the extra support themselves. Continuity was very important as the people that they care for would appreciate having the same person each time. This was echoed by the focus group participants, who all agreed it was a good idea, but would only work with consistency. Some however said that they appreciated the opportunity to get the person that they care for out of the house and would rather go to the memory clinic. The topic of driving came up in one of the focus groups, two of the respondents said that their partner did all the driving and now they can't. For this reason they would appreciate support in the home, rather than having to go to the memory clinic. In the same focus group, concerns were shared about the lack of medical knowledge of the support worker.

**4) The patient and any carer / family member would then see a doctor specialising in dementia. At the moment this happens in different places, sometimes at an outpatient clinic and sometimes a home visit. The new plan is that this will usually happen in a local GP surgery, but if a person is very frail or for other reasons, there would still be scope for home visits. Would this be helpful or not? (Please explain your answer)**

**People living with dementia:** All the respondents said that this would be helpful, especially the home visits. Although having appointments at GP Surgeries would also be helpful, as they are familiar places.

**Carers:** 95% of the survey respondents said that this would be helpful. The majority of them specifically said that the home would be preferable, but some said they would be happy to go to the GP Surgery as it is close by and familiar for the person that they are caring for. Concerns were shared in one of the focus groups, saying that there may not be enough specialists for home visits, would this then mean that appointments aren't as frequent. In another one of the focus groups, participants said that the person that they care for may not appreciate going to a certain part of the GP for their memory concerns, as they may not want everyone knowing about their condition.



**5) A doctor specialising in dementia will still do the great majority of diagnosis of dementia, any prescribing of medication and, with the memory service, carry out initial reviews. After this, the plan is for routine medication reviews to be carried out by GPs and practice nurses, referring to specialist services as required. Would this be helpful or not? (Please explain your answer)**

**People living with Dementia:** 11 of the 14 survey respondents thought this would be helpful. The three that said that it wouldn't be helpful, were concerned about the lack of expertise of the GPs and practice nurses. There were concerns from one of the focus groups, saying that it's hard for them to get appointments at their GP Surgery, so would it be equally hard for them to book routine medication reviews.

**Carers:** All the respondents felt that this would be helpful. There was no mention of how the GP Surgery is viewed as a 'safe' environment over the Memory Clinic. However, many respondents left further responses saying that they would find home visits very helpful, as the person that they care for is either frail or can no longer drive, so they have to take them to appointments. The participants in one of the focus groups shared concerns about the knowledge of the GPs and practice nurses.

**6) The support worker would make sure that everyone diagnosed with dementia, and the family, receives information, advice and support about living with dementia, and knows about the different help and activities available in Leeds and the local area. The Memory Service will continue to offer group sessions about living with dementia; and a treatment known as "cognitive stimulation therapy" which is based on keeping active, and is not a drug treatment. In future, the memory service will be able to offer these group sessions to more people. This is because of the plan to reduce the amount of work they do to review medication. Do you think this is the right approach to help people and families living with dementia, or not? (Please explain your answer)**

**People living with dementia:** All the respondents thought this was the right approach, one further said that it was good to try a different approach. The participants in one of the focus groups said that this sort of information should be available immediately after diagnosis.

**Carers:** 90% of the survey respondents said that this was the right approach. Some left further comments saying that it's good for the person living with dementia and carer to be helped together, as this can combat the assumption that people who are living with dementia are 'mad'. Some said that the group therapy may help combat isolation. The respondents who said that they weren't so sure about the approach said that this was because they would rather see the person they care for receiving one-to-one support, over group therapy. One respondent said they had a bad experience in the past, but didn't go into more detail about this. The carers in the focus groups said that this would be a good chance for them to have a break from their caring. One carer who currently uses the CST service said that it gives herself and the other carers a break, as they all go out together and have continued to stay in touch ever since.

**7) What do you think about the name Eldercare Facilitator for the support worker? If you would like us to use a different name for the role please suggest a different one.**

Responses to this question were mixed. The majority of people didn't like the name, as they didn't think that it explained what the job entailed. People find 'eldercare' difficult to understand and said that not everybody who has dementia is elderly. They said why not just use the word 'dementia'.



People considered the word 'facilitator' to be jargon. They suggested using 'support worker' instead. Common suggestions for a different title were 'memory support worker' or just 'support worker'.

### 8) What support works well for you at the moment and what could be improved?

**People living with Dementia:** The respondents all said that they were happy with the support that they receive. One gave additional praise for the Alzheimer's Society. One said that they didn't receive any support, but they were still happy with the level of support that they received. The respondents in the Shakti focus group said that they didn't really get any support from healthcare professionals. This was echoed by another two South Asian survey respondents who said that they felt the same.

**Carers:** 77% of respondents felt that they were well supported. This was mainly through the services provided by the Alzheimer's Society, Maicare and Carers Leeds. Those that didn't feel supported said that they had to do a lot of work in order to find support services, support isn't 24/7 and they don't get enough breaks as carers. One of the Shakti focus group members said that her husband used to attend a dementia café. At one of the cafes, he took his turban off and no one assisted him in getting in back on, as they weren't aware of the severity of his actions. She and the rest of the group said that support needs to be culturally sensitive.

## 6. Conclusion

The findings indicate that:

- the GP should be the first point of contact for those who are suffering with memory problems;
- there is a lack of confidence about GPs clinical knowledge about dementia and that GPs would listen to patients and carers;
- CT scans should become the usual procedure at the initial stage of diagnosis. It was felt that they were very helpful in identifying the type of dementia and other illnesses;
- follow up support and discussion is needed after the CT scan. The impact of being diagnosed through a scan with out after care support could be devastating for patients and carers;
- the implementation of a support worker once someone has been diagnosed with dementia is a good idea. Particularly if it is someone who can offer support within the home, as some people who have dementia experience difficulties leaving the home;
- the focus for participants was having support at home rather than the type of support provided;
- the lack of medical knowledge of the support worker was a concern but the majority would appreciate the extra support either way;
- a strong preference was expressed about seeing specialists in the home, or the GP Surgery due to its familiarity;
- privacy and anonymity were important as there were concerns about other patients seeing people going into a certain part of the GP Surgery and knowing that they are having memory problems;
- medication reviews being carried out in GP Surgeries by GPs and/or practice nurses was a good idea but there were concerns about the staff expertise on dementia,
- the Cognitive Stimulation Therapy (CST) service was considered a good idea;
- the job title 'eldercare facilitator' needs to be changed, preferences were 'memory support worker', or 'support worker';



- overall people felt well supported. Although, the support that they referenced came from the third sector, rather than healthcare professionals; and
- support provided needs to be culturally sensitive, and certain communities appear to be under supported.

### **Appendix 1**

## **Living with dementia Consultation on dementia diagnosis and help after diagnosis**

The NHS in Leeds is working to improve dementia diagnosis and support for people with dementia and families after diagnosis. At the moment we know that, whilst some people feel well-supported, others have been left alone to manage with the diagnosis. The waiting times for services have also been very variable depending on which part of Leeds you live in.

We have specialist NHS services in Leeds, provided by doctors specialising in dementia and the Leeds memory service. We know that people living with dementia appreciate and value these services. However, older people with dementia need all the different NHS services to work more closely together, as many are living with other health conditions and illnesses.

Therefore, our new plan proposes that dementia diagnosis and support after diagnosis will be centred on GP practices; with the doctors specialising in dementia and the memory service coming in to run local clinics. At the moment many people travel to the specialist memory clinics for appointments.

Our ambition is to identify, diagnose and support more people to live well with dementia. Therefore the plan is that new staff will be added to local teams. These staff roles are “support workers”, with the job to support people through diagnosis and ensure people have information and support afterwards. This role has worked well elsewhere in England, and there is evidence that it has helped to reduce hospital admissions. So investing in the new staff could both improve the quality of people’s lives and, overall, pay for itself.

We are consulting further to hear the views and concerns of people living with dementia. We want to better understand any potential effect that the proposed changes might have. We will then adjust the plans accordingly.

### **What will happen to my views?**

We will use your feedback alongside feedback from GPs, the specialist mental health services, and others to develop the proposed plan into its final version.

Your views will remain anonymous, which means no-one will see your name in connection with this questionnaire. If you would like help to complete this questionnaire or would like it in another language or format please contact us by phone: 0113 8432900 or email: [leedsnorthccg@nhs.net](mailto:leedsnorthccg@nhs.net)

Thank you for taking the time to complete this form. We would like to have all your views by **3 May 2014**.

Please return this form to:

Freepost RTEH-ZTXY-HALJ  
Leeds North Clinical Commissioning Group  
Leafield House  
107-109 King Lane, Leeds, LS17 5BP



### Questionnaire

Are you completing this survey as **someone living with dementia** or as a **carer** – please circle

1.	<p>In the new plan, your GP would remain as the first point of contact for concerns about memory problems, and carry out the initial tests (a short memory test and some blood tests).</p> <p>Do you think this is the right approach, or should we make more changes? (Please explain your answer)</p>
2.	<p>At the moment, some GPs refer for a scan (CT head scan) at this initial stage. This will now become the usual procedure, unless you've had a scan recently or there is a good individual reason not to refer. Scans occasionally detect other illnesses that cause memory problems and can help diagnose the type of dementia.</p> <p>We want to make referral for scans more consistent, what are your thoughts? (Please explain your answer)</p>
3.	<p>The next step for diagnosis and support is for the GP to make a referral to the memory service. In the new plan, patients and their families would receive a visit at home from a support worker. They would listen to concerns, gather initial information, and offer reassurance and support. The support worker role will not be a qualified medical person, but would refer to a memory nurse or other medical professional if required.</p> <p>Do you think this is would be helpful or not? (Please explain your answer)</p>



4.	<p>The patient and any carer / family member would then see a doctor specialising in dementia. At the moment this happens in different places, sometimes at an outpatient clinic and sometimes a home visit. The new plan is that this will usually happen in a local GP surgery, but if a person is very frail or for other reasons, there would still be scope for home visits.</p> <p>Would this be helpful or not? (Please explain your answer)</p>
5.	<p>A doctor specialising in dementia will still do the great majority of diagnosis of dementia, any prescribing of medication and, with the memory service, carry out initial reviews. After this, the plan is for routine medication reviews to be carried out by GPs and practice nurses, referring to specialist services as required.</p> <p>Would this be helpful or not? (Please explain your answer)</p>
6.	<p>The support worker would make sure that everyone diagnosed with dementia, and the family, receives information, advice and support about living with dementia, and knows about the different help and activities available in Leeds and the local area.</p> <p>The Memory Service will continue to offer group sessions about living with dementia; and a treatment known as “cognitive stimulation therapy” which is based on keeping active, and is not a drug treatment. In future, the memory service will be able to offer these group sessions to more people. This is because of the plan to reduce the amount of work they do to review medication.</p> <p>Do you think this is the right approach to help people and families living with dementia, or not? (Please explain your answer)</p>
7.	<p>What do you think about the name Eldercare Facilitator for the support worker? If you would like us to use a different name for the role please suggest a different one.</p>
8.	<p>What support works well for you at the moment and what could be improved?</p>
9.	<p>Do you have any other comments or concerns you would like to make?</p>



### Equality monitoring form

So that we provide the best services for all of our communities, and to make sure that we do not knowingly discriminate against any section of our community, it is important for us to gather the following information. No personal information will be released when reporting statistical data and data will be protected and stored securely in line with data protection rules.

#### What is the first part of your postcode? e.g. LS28, LS13

Please enter here:	<input type="checkbox"/> Prefer not to say
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Do you pay for your prescription?  Yes  No

#### What sex are you?

<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Prefer not to say
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#### Transgender - is your gender identity different to the sex you were assumed to be at birth?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Prefer not to say
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#### Pregnancy and maternity

<input type="checkbox"/> I am pregnant	<input type="checkbox"/> I have given birth within the last 26 weeks
<input type="checkbox"/> Not applicable	<input type="checkbox"/> Prefer not to say

#### What is your age?

<input type="checkbox"/> Under 16	<input type="checkbox"/> 16 - 25	<input type="checkbox"/> 26 - 35
<input type="checkbox"/> 36 - 45	<input type="checkbox"/> 46 - 55	<input type="checkbox"/> 56 - 65
<input type="checkbox"/> 66 - 75	<input type="checkbox"/> 76 - 85	<input type="checkbox"/> 86 +
<input type="checkbox"/> Prefer not to say		

#### What is your sexual orientation?

<input type="checkbox"/> Bisexual (both sexes)	<input type="checkbox"/> Heterosexual/straight (opposite sex)
<input type="checkbox"/> Gay man (same sex)	<input type="checkbox"/> Lesbian/gay woman (same sex)
<input type="checkbox"/> Prefer not to say	

#### Do you consider yourself to belong to any religion?

<input type="checkbox"/> Buddhism	<input type="checkbox"/> Christianity	<input type="checkbox"/> Hinduism
<input type="checkbox"/> Islam	<input type="checkbox"/> Judaism	<input type="checkbox"/> Sikhism
<input type="checkbox"/> No religion	<input type="checkbox"/> Prefer not to say	
Other (please state)		

#### What is your ethnic background?

Asian, or Asian British	Black, or Black British	Mixed/ multiple Ethnic groups	White	Other
<input type="checkbox"/> Chinese	<input type="checkbox"/> African	<input type="checkbox"/> Asian & White	<input type="checkbox"/> British	<input type="checkbox"/> Arab
<input type="checkbox"/> Indian	<input type="checkbox"/> Caribbean	<input type="checkbox"/> Black African & White	<input type="checkbox"/> Gypsy/Traveller	<input type="checkbox"/> Other
<input type="checkbox"/> Pakistani	<input type="checkbox"/> Other	<input type="checkbox"/> Black Caribbean & White	<input type="checkbox"/> Irish	
<input type="checkbox"/> Other		<input type="checkbox"/> Other	<input type="checkbox"/> Other	

If any other ethnic background, please state here:



<input type="checkbox"/> Prefer not to say
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**Do you consider yourself to have a disability? Please tick all that apply**

Under the Equality Act 2010 a disability is defined as ‘a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person’s ability to carry out normal day to day activities’.

<input type="checkbox"/> Long-standing illness or health condition e.g. cancer, diabetes, HIV, etc.		
<input type="checkbox"/> Learning disability/difficulty	<input type="checkbox"/> Mental Health condition	<input type="checkbox"/> Physical or mobility Visual
<input type="checkbox"/> Hearing	<input type="checkbox"/> Visual	<input type="checkbox"/> Other (please state)
<input type="checkbox"/> Prefer not to say		

**Do you look after, or give any help or support to a family member, friend or neighbour because of long term physical disability, mental ill-health or problems related to old age?**

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Prefer not to say
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**What is your relationship status?**

<input type="checkbox"/> Marriage/civil partnership	<input type="checkbox"/> Live with partner	<input type="checkbox"/> Single	<input type="checkbox"/> Widowed
<input type="checkbox"/> Prefer not to say	<input type="checkbox"/> Other Please specify:		

**Thank you for taking the time to complete this form.**

We would like to have all your views by 3 May 2014

**Please return this form to:**

Freepost RTEH-ZTXY-HALJ  
 Leeds North Clinical Commissioning Group  
 Leafield House  
 107-109 King Lane  
 Leeds, LS17 5BP

**Appendix 2**

**Engagement**

Organisations visited for survey completion and focus groups:

- Alzheimer’s Society
- Carers Leeds
- Bangladeshi Carers Group – Health for All
- Carers UK
- Chapel Allerton Good Neighbours
- Meanwood Elderly Neighbourhood Action
- Maecare
- Leeds Jewish Welfare Board
- Shakti Project – Health for All
- Leeds Irish Health and Homes
- Action for Gipton Elderly
- OPAL Carers Support Group
- Trinity Network



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

- Crossgates Good Neighbours Café
- Touchstone
- Aireborough Voluntary Services to the Elderly with Disabilities

### **Appendix 3**

#### Shakti Project – Health for All

9<sup>th</sup> April 2014

Focus group with eight women, six of whom were carers and two were people living with dementia. Seven were Sikh and one was Muslim.

- 1) In the new plan, your GP would remain as the first point of contact for concerns about memory problems, and carry out initial blood tests (a short memory test and some blood tests). Do you think this is the right approach, or should we make some more changes?

This is the right approach, don't know where else you would go. One lady said that she has concerns about her memory, but doesn't want to go to the GP as she may be told that she can't drive anymore. Her being able to drive is very important to her, as she drives her elderly mother around and it is the only way she can get out to visit family and friends.

- 2) At the moment, some GPs refer for a scan (CT head scan) at this initial stage. This will now become the usual procedure, unless you've had a scan recently or there is a good individual reason not to refer. Scans occasionally detect other illnesses that cause memory problems and can help diagnose the type of dementia. We want to make referral for scans more consistent, what are your thoughts? (Please explain your answer)

This seems like a good idea. Scans are very important in diagnosis, so this will be particularly helpful. However the scan must be followed up. One lady shared her experience of not having any follow-up from her scan about her actual condition, just that she can't drive anymore. She said that the scan shouldn't be all that GPs rely on for diagnosis, they should also talk to the patient about how they're feeling. She also felt that the GP didn't understand her properly, and she was told that there wasn't any medication available for her.

- 3) The next step for diagnosis and support is for the GP to make a referral to the memory service. In the new plan, patients and their families would receive a visit at home from a support worker. They would listen to concerns, gather initial information, and offer reassurance and support. The support worker role will not be a qualified medical person, but would refer to a memory nurse or other medical professional if required. Do you think this is would be helpful or not? (Please explain your answer)

A Support Worker would be very helpful. It would be good if they also took the person living with dementia out, to give the carer a break.

- 4) The patient and any carer / family member would then see a doctor specialising in dementia. At the moment this happens in different places, sometimes at an outpatient clinic and sometimes a home visit. The new plan is that this will usually happen in a local GP surgery, but if a person is very frail or for other reasons, there would still be scope for home visits. Would this be helpful or not? (Please explain your answer)

Appointments at home would be the most useful. Appointments at the GP would be helpful, as you know where you're going. If a person has to travel far from their home for an appointment, this makes them more vulnerable, so home visits are preferable.



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

- 5) A doctor specialising in dementia will still do the great majority of diagnosis of dementia, any prescribing of medication and, with the memory service, carry out initial reviews. After this, the plan is for routine medication reviews to be carried out by GPs and practice nurses, referring to specialist services as required. Would this be helpful or not? (Please explain your answer)

The lady who said she had been diagnosed with dementia said that she hadn't been told about the Memory Clinic. The GP Surgery would be the best place to go, as it is familiar. The Memory Clinic wouldn't be too bad, as long as transport is provided.

- 6) The support worker would make sure that everyone diagnosed with dementia, and the family, receives information, advice and support about living with dementia, and knows about the different help and activities available in Leeds and the local area. The Memory Service will continue to offer group sessions about living with dementia; and a treatment known as "cognitive stimulation therapy" which is based on keeping active, and is not a drug treatment. In future, the memory service will be able to offer these group sessions to more people. This is because of the plan to reduce the amount of work they do to review medication. Do you think this is the right approach to help people and families living with dementia, or not? (Please explain your answer)

Yes, this is a really good idea, but transport would need to be provided for some people.

- 7) What do you think about the name Eldercare Facilitator for the support worker? If you would like us to use a different name for the role please suggest a different one.

Not a problem in terms of translation, but the word 'eldercare' doesn't really make sense. It would be better to just say 'dementia'.

- 8) What support works well for you at the moment and what could be improved?

The support groups that are available are really helpful, as they allow people to meet who have similar needs and not feel like they are alone. Groups need to be culturally sensitive, one lady shared an experience of her husband removing his turban in a dementia café and none of the staff helped him to get it back on, as they didn't realise the significance of what he had just done.

### Remember-when, Dementia Carers

15th April 2014

Focus group with seven carers, all female, white British.

- 1) In the new plan, your GP would remain as the first point of contact for concerns about memory problems, and carry out initial blood tests (a short memory test and some blood tests). Do you think this is the right approach, or should we make some more changes?

This is the right approach. At the moment referrals are made to the Memory Clinic, and there can be long waiting times for appointments, so this is a much better approach. The GP as a first point of contact seems logical, although they must listen to people's concerns about memory loss and not dismiss it as 'old age'.

- 2) At the moment, some GPs refer for a scan (CT head scan) at this initial stage. This will now become the usual procedure, unless you've had a scan recently or there is a good individual reason not to refer. Scans occasionally detect other illnesses that cause memory problems and can help diagnose the type of



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

dementia. We want to make referral for scans more consistent, what are your thoughts? (Please explain your answer)

This seems like a good idea. Scans are very important in diagnosis, so this will be particularly helpful.

- 3) The next step for diagnosis and support is for the GP to make a referral to the memory service. In the new plan, patients and their families would receive a visit at home from a support worker. They would listen to concerns, gather initial information, and offer reassurance and support. The support worker role will not be a qualified medical person, but would refer to a memory nurse or other medical professional if required. Do you think this would be helpful or not? (Please explain your answer)

There were concerns about the Support Worker not having any medical knowledge, so they would be of little help before diagnosis. However, after diagnosis they will be useful, especially if you are given a named contact. 24 hour support would be particularly helpful, as dementia doesn't have time off. It would be better to have a Support Worker coming into the home, rather than having to go to the Memory Clinic. It would also be of benefit to the carer, as it gives them some support in terms of having information shared with them about helpful resources. One carer said that she likes having to go out to the Memory Clinic, as it gets her and her husband out of the house together. Another said that she doesn't drive, and her partner is no longer able to, so having home visits would work really well for them. This led to a conversation about driving, where a further carer said that they no longer have access to a car, as their husband used to do all the driving and they can no longer drive. Experiences were shared about past Support Workers coming into the home, as some have been really good and helpful, and some haven't been helpful at all. It would be helpful if each person got a support worker assigned to them, as it can take a while for someone who is living with dementia to build up trust in new people. All the group agreed that dementia isn't one size fits all, and support needs to be tailored to individual need.

- 4) The patient and any carer / family member would then see a doctor specialising in dementia. At the moment this happens in different places, sometimes at an outpatient clinic and sometimes a home visit. The new plan is that this will usually happen in a local GP surgery, but if a person is very frail or for other reasons, there would still be scope for home visits. Would this be helpful or not? (Please explain your answer)

This would be very helpful, as sometimes it can be hard to get a person living with dementia out of the home, especially to a new place that they aren't familiar with (Memory Clinic). At least they are familiar with the GP Surgery. Some people may not want to share the fact that they are living with dementia, they may not be happy going to a particular part of the GP Surgery which is specifically designed for dementia services. It is also important for the carer to have the opportunity to speak to a healthcare professional privately about the person that they care for and their needs, as often they can't say what they want to say.

- 5) A doctor specialising in dementia will still do the great majority of diagnosis of dementia, any prescribing of medication and, with the memory service, carry out initial reviews. After this, the plan is for routine medication reviews to be carried out by GPs and practice nurses, referring to specialist services as required. Would this be helpful or not? (Please explain your answer)

It would be helpful getting prescriptions from the GP Surgery. Some already do, and find it much easier. Some concerns about the GPs and Practice Nurses carrying out the reviews, do they know what they're doing? If they did have any concerns, they would have to be passed onto a specialist service and reassurance that they will be listened to.



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

- 6) The support worker would make sure that everyone diagnosed with dementia, and the family, receives information, advice and support about living with dementia, and knows about the different help and activities available in Leeds and the local area. The Memory Service will continue to offer group sessions about living with dementia; and a treatment known as “cognitive stimulation therapy” which is based on keeping active, and is not a drug treatment. In future, the memory service will be able to offer these group sessions to more people. This is because of the plan to reduce the amount of work they do to review medication. Do you think this is the right approach to help people and families living with dementia, or not? (Please explain your answer)

Yes, it seems like a good service and every little helps. Those that said that they had used the service before, said that they had a really good experience. Those that are living with dementia are separated from their carers, so this gives the carers a break as well as stimulation for those living with dementia. After the course finished, the carers stayed in touch. The only downside is that the stimulation needs to continue after the course has finished, this can be time consuming and difficult to maintain.

- 7) What do you think about the name Eldercare Facilitator for the support worker? If you would like us to use a different name for the role please suggest a different one.

It's a bit of a mouthful. Support Worker would suffice. Facilitator is management jargon, so not appropriate. Eldercare just doesn't work. The worker will be offering social support, as opposed to diagnostic support, so this needs to come through in their job title.

- 8) What support works well for you at the moment and what could be improved?

When you meet different professionals, you often have to repeat the same information, it would be helpful if they shared information, so you can focus more on the matter at hand. The Alzheimer's Society have been fantastic, they have information on everything, and if they don't, they'll get it for you.

Leeds Irish Health and Homes

1<sup>st</sup> May 2014

Focus group with four individuals who are living with dementia, two individuals who run the group and one volunteer.

1. In the new plan, your GP would remain as the first point of contact for concerns about memory problems, and carry out the initial tests (a short memory test and some blood tests). Do you think this is the right approach, or should we make more changes?

Yes, this is the right approach. People tend to know their GPs better than going to a stranger. They also the surgery well, so can't get as lost or confused. It's mainly older people who have the dementia and so it's better to go to a familiar place to feel at ease. You want to go somewhere local to the people. The doctor is also known by the patient. So they can easily note any changes in the patient, as refer them to a specialist. Also, if there are changes associated with dementia these can also be noted by the GP to help with further diagnosis and support.

2. At the moment, some GPs refer for a scan (CT head scan) at this initial stage. This will now become the usual procedure, unless you've had a scan recently or there is a good individual reason not to refer. Scans occasionally detect other illnesses that cause memory problems and can help diagnose the type of dementia. We want to make referral for scans more consistent, what are your thoughts?



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

The process at the moment is very long. It can be a long procedure between being diagnosed and getting the support you need. It can take weeks in between. Because of having dementia one can miss their appointment. They need extra help so that they can make their appointments, not just write it down. Maybe they need someone to go with them, especially those who are on their own (isolated) need extra support to remind them of these things. They need extra help so that they can make their appointments. And so it should be a standard procedure to have a CT scan even if they don't have memory issues as it can flag up other issues. My father was diagnosed with dementia, but the scan also showed strokes. If someone was there to for the individual to call the individual up now and then to check up on them to see if things are ok that would be helpful

3. The next step for diagnosis and support is for the GP to make a referral to the memory service. In the new plan, patients and their families would receive a visit at home from a support worker. They would listen to concerns, gather initial information, and offer reassurance and support. The support worker role will not be a qualified medical person, but would refer to a memory nurse or other medical professional if required. Do you think this would be helpful or not?

Yes, it would be helpful if someone wrote things down/make notes, when something comes up or something is important to people/ those with dementia don't have to repeat themselves, as they can forget what it is important it is vital that people write things down for the individuals. Once the support worker has left they don't know what was said, so it is very important someone writes things down. A lot of people are living on their own, they may not even know they have dementia, they need all the help they can get.

4. The patient and any carer / family member would then see a doctor specialising in dementia. At the moment this happens in different places, sometimes at an outpatient clinic and sometimes a home visit. The new plan is that this will usually happen in a local GP surgery, but if a person is very frail or for other reasons, there would still be scope for home visits. Would this be helpful or not?

Yes it would be helpful. Home visits are good, as people may forget their appointment. So it can be better if someone came to visit them. In my experience, a doctor won't come out to the individual as they aren't classed as having a physical issue. But the GP surgery would be easier to get to as it's local. It's all good as well, but what if the times to see the GP is limited? What if there aren't enough specialists? Or don't have time on a specific date and time to come see the patient. Misinformation? No information out there? Maybe a fact sheet as soon as you're concerned about your memory. If the waiting time for someone to get support is long, one can read up on the information about dementia as a way of self-help.

5. A doctor specialising in dementia will still do the great majority of diagnosis of dementia, any prescribing of medication and, with the memory service, carry out initial reviews. After this, the plan is for routine medication reviews to be carried out by GPs and practice nurses, referring to specialist services as required. Would this be helpful or not?

Yes it would be helpful. Concerned that we are putting a lot of strain in the GPs. It's quite difficult to get an appointment with the GP anyway let alone for something like dementia, worried that you only get 10 min appointments. So it's great in theory, but then GPs need a lot more training and time to work with those with dementia. The sooner people go to the GP with memory loss, the sooner they can get help. Still a stigma attached to it.

6. The support worker would make sure that everyone diagnosed with dementia, and the family, receives information, advice and support about living with dementia, and knows about the different help and activities available in Leeds and the local area.



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

The Memory Service will continue to offer group sessions about living with dementia; and a treatment known as “cognitive stimulation therapy” which is based on keeping active, and is not a drug treatment. In future, the memory service will be able to offer these group sessions to more people. This is because of the plan to reduce the amount of work they do to review medication. Do you think this is the right approach to help people and families living with dementia, or not?

Yes it is the right approach, we agree. But it would be better if they sped up the procedure from diagnosis to support. A basic fact sheet, as the diagnosis can be upsetting and daunting for both families and individuals themselves. It can be difficult and scary coming to a group. It can give the carers a break when the individuals go to group sessions, obviously, if the carer wants to come along they can. It would be nice to have transport given to the groups, so the individuals don't get lost coming to the groups, and actually can attend the groups.

7. What do you think about the name Eldercare Facilitator for the support worker? If you would like us to use a different name for the role please suggest a different one.

No don't think it's a good name. A bit of a tongue twister. And there are a lot of people who are diagnosed with dementia who are not elderly. A lot of people even over 60 don't see themselves as old. Support worker is fine and lovely. Easy to understand? And maybe the name needs to explain what the person with the role of the support worker does. Eldercare Facilitator is a scary name and does not explain in simple terms what the person does.

8. What support works well for you at the moment and what could be improved?

There needs to be dementia awareness for everyone. The community need to be more aware, so do workers and employees. There needs to be community work and training for workers, to know how to work with those with dementia and older people. Put yourself in the shoes who have dementia. The groups are good, gives them a sense of belonging, and breaks the weeks up, individuals look forward to the group, gives carers respite at the same time. A lot of people need to know what they are entitled to, needs to be signposted. The length of time between diagnosis and actual help and support needs to be shortened. Clinics are difficult to get to, so transport may need to be provided or the clinics need to be more local and accessible. There needs to be more information with leaflets.

### **Appendix 4**

#### **Carers Equality Monitoring**

Gender	Total
Female	26
Male	9
Prefer not to say	0
Unanswered	12
Grand Total	47

Pregnancy/Maternity	Total
N/A	9
Given birth in last 26 weeks	0
I am pregnant	0
Prefer not to say	0
Unanswered	38
Grand Total	47

Religion or belief	Total
Christianity	24
Sikh	1
Hindu	2
Islam	2
No religion	11
Prefer not to say	0
Unanswered	11



Grand Total	47
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Ethnic Background	Total
British	41
Irish	1
Prefer not to say	0
Unanswered	5
Grand Total	47

Transgender	Total
No	9

  

Relationship Status	Total
Prefer not to say	0
Marriage/civil partnership	26
Unanswered	38
Single	3
Grand Total	47
Widowed	2
Live with partner	1

  

Prescriptions	Total
Prefer not to say	0
Unanswered	26
Yes	15
Grand Total	47
Unanswered	8
Grand Total	13
Grand Total	47

Age group	Total
Under 16	0
16-25	0
26-35	0
36-45	1
46-55	6
56-65	9
66-75	11
76-85	11
86+	3
Prefer not to say	0
Not answered	6
Grand Total	47

Do you look after anyone?	Total
Yes	41
No	0
Prefer not to say	0
Unanswered	6
Grand Total	47

Sexuality	Total
Heterosexual	9
Gay man	0
Lesbian/gay woman	0
Bisexual	0
Prefer not to say	1
Unanswered	38
Grand Total	47

Type of disability	Total
Long-standing illness or health condition	3
Physical/mobility	1
Hearing	1
Learning	
disability/mental health condition	0
Visual	0
Prefer not to say	1
Unanswered	41
Grand Total	47

Clinical Commissioning Group	Total
West	25
North	9
South and East	7
Not answered	6
Grand Total	47

**Appendix 5**

**People with Living with Dementia Equality Monitoring**



## Living with Dementia: Consultation on dementia diagnosis and help after diagnosis

Gender	Total
Female	8
Male	5
Prefer not to say	0
Unanswered	1
<b>Grand Total</b>	<b>14</b>

Ethnic Background	Total
British	9
Indian	4
Black Caribbean	1
Prefer not to say	0
Unanswered	1
<b>Grand Total</b>	<b>14</b>

Pregnancy/Maternity	Total
N/A	5
Given birth in last 26 weeks	0
I am pregnant	0
Prefer not to say	0
Unanswered	0

  

Relationship Status	Total
Marriage/civil partnership	6
Widowed	2
Live with partner	1

  

Transgender	Total
Single	1
Prefer not to say	1
Yes	0
Unanswered	3
Prefer not to say	0
<b>Grand Total</b>	<b>14</b>

Religion or belief	Total
Christianity	6
Sikh	2
Hindu	2
Islam	2
No religion	3
Prefer not to say	0
Unanswered	1
<b>Grand Total</b>	<b>14</b>

Age group	Total
Under 16	0
16-25	0
26-35	0
36-45	0
46-55	1
56-65	3
66-75	1
76-85	6
86+	2
Prefer not to say	0
Not answered	1
<b>Grand Total</b>	<b>14</b>

Sexuality	Total
Heterosexual	4



Gay man	0
Lesbian/gay woman	0
Bisexual	0
Prefer not to say	1
Unanswered	9
<b>Grand Total</b>	<b>14</b>

<b>Pay for prescriptions</b>	<b>Total</b>
No	9
Yes	2
Unanswered	3
<b>Grand Total</b>	<b>14</b>

<b>Clinical Commissioning Group</b>	<b>Total</b>
North	6
West	4
South and East	2
Not answered	2
<b>Grand Total</b>	<b>14</b>

<b>Type of disability</b>	<b>Total</b>
Long-standing illness or health condition	2
Physical/mobility	2
Hearing	1
Learning disability/mental health condition	0
Visual	0
Prefer not to say	0
Unanswered	9
<b>Grand Total</b>	<b>14</b>

<b>Do you look after anyone?</b>	<b>Total</b>
No	8
Yes	1
Prefer not to say	0
Unanswered	5
<b>Grand Total</b>	<b>14</b>

