

# Work Plan Priority Dementia



# Work Plan Priority - Dementia

## Executive Summary

### Background

Healthwatch set up this task group in September 2013 to compliment work already done by the local authority and the CCG. One of the main findings from the listening event hosted by LINK in 2011, was lack of support information provided at diagnosis stage. This incurred changes within the dementia care pathway - one of them being the practical and emotional support for carers and / or people with dementia which included the allocation of information packs at the point of diagnosis. The consensus of the task group was to find out what people with dementia and / or their carers felt about the information packs. A questionnaire was devised and sent out to the above target audience via networks within the borough in order to obtain the views of as many people as possible facing this condition.

### Why should this be a priority for Healthwatch St Helens?

The topic was the focus of a Public Health Annual Report in 2012, and is a joint health & social care concern. It is also one of the Health & Well Being strategy priorities - 'Support for People with Dementia'. Healthwatch St Helens was also invited to be part of a sub-group of the Health & Wellbeing Board, a Dementia Project Group which meets regularly to feedback on an ongoing action plan to address all stages of the pathway for people with dementia, which helps to avoid any overlap or duplicated work. One of the pathway concerns were referrals of people with possible dementia for further consultation and iPads were provided to GPs and Health Professionals assist with this. The available data for St Helens is that the profile for dementia shows a slight over-incidence of dementia compared to Halton as a proportion of the population. The latest up-to-date profile for St Helens is currently underway.

### Consultation method

The task group agreed to a small project due to the restricted timescale and also that the majority of actions should be progressed via the sub-group of the HWBB as mentioned above. They reached a consensus on the questions being asked and these were then distributed via email to the groups in contact with people with dementia and their carers, plus other networks at the beginning of March. These included some care homes and the Social Inclusion Network and the Borough Forum with ad hoc comments from the Carers Centre.

### Conclusion

The majority of questionnaires were returned by Alzheimer's Society support groups. Considering the short timescale, email was the quickest way of distribution, and this may not have been the most effective method of motivating people to complete questionnaires. Most people felt the information packs were very good and attractive on the eye. Others did make comments which reflected previous comments in the 2011 listening event - that information needs to be coordinated, and there was no information on Picks disease. In addition there is a need for emotional as well as practical support.

## Introduction

The term dementia describes a set of symptoms that include loss of memory, confusion and problems with speech and understanding. Dementia is progressive which means the symptoms will gradually get worse. Dementia has a significant impact upon the whole life of the person who has it, families, carers and friends.

The aim of the task group was to look at areas within the dementia care pathway from emerging symptoms through diagnosis to managing the condition, and identify any areas which needed looking at.

Healthwatch St. Helens set up a 'Dementia' task group in September 2013 to scope its ideas. Due to illness and holidays of volunteers, the group reconvened in November.

Members looked at the whole care pathway for dementia patients and pinpointed where difficulties were at each stage of the pathway. These questions (see Appendix 2) were put to the Director of Adult Services and have been turned into actions that are part of a multi-agency action plan drawn up by the Dementia Project group – a sub-group of the Health & Well Being Board. Some of the actions were due to be reviewed in January, March and May 2014. These included reviewing the approach of GPs and practices to concerns over memory problems, reviewing the effect of having a Dementia Advisor, use of iPads as a screening tool, implications of ACTs on other service areas, and to assess the impact of the and outcomes of the Dementia Care Advisors.

This avoided any overlap or duplication on any current work done or in progress, by the local authority-led group.

By December – organisations including the Alzheimer's Society, Age UK, Dementia Links, Looking Forward Group, and the Carers Centre signed up to identifying the gaps and what additional actions need looking at, and two topics emerged:

- the use of iPads to check for symptoms of dementia to enable GPs to make more accurate referrals to 5BP for a diagnosis and
- the effectiveness of the information packs which are provided to people shortly after diagnosis

The task group drafted up a questionnaire (please see appendix) which was sent electronically via the task group member organisations to groups or individuals they are attached to. This included the groups named above, and via the SIN network, Borough Forum Carers UK and a handful of care homes.

## Why should this be a priority for Healthwatch?

Dementia is a health and social concern nationally and locally. A national Dementia Challenge was launched in 2012 to make improvements to the lives of people living with dementia, their families and carers, building on progress made through the national dementia strategy (2009).

Dementia has also been identified as a local priority within the St Helens Health & Well Being Strategy. An implementation plan for the strategy has been developed and a Dementia Project group was set up by Adult and Social care of which Healthwatch is a representative.

A number of Healthwatch St Helens' members and partners represent or deliver services for people with dementia and their carers. These include the Alzheimer's Society, MIIND, Carers Centre, 5BP, Senior Voice, Age UK Mid Mersey, St Helens & Knowsley Hospital Trust, St Helens Clinical Commissioning Group, Kershaw Centre, St Helens Council.

Healthwatch St Helens has the remit to bring together this broad range of expertise to improve access to services and quality of life for people with dementia. Healthwatch St. Helens set up a task group with named partners – some of which are above to act as a critical friend in order to identify the stages where support could be improved.

In this piece of work the Dementia task group looked at the quality of information packs provided at the point of or just after diagnosis. In addition there has been an increase in referrals from GPs to the Memory Clinic. The introduction of an iPad application which GPs and health professionals use as an initial diagnostic tool could be a possible reason for the increase in referrals.

Finally, the support groups currently available are limited to 3 or 4 which are short-term funded – these are supported by Alzheimer's Society, Age UK Mid Mersey, and the St. Helens Carers Centre.

### What does the data tell us?

Dementia is most common in older people, affecting 5% of people over the age of 65 and 20% of people over the age of 80. Data from the Joint Strategic Needs Assessment (JSNA) identified that due to the ageing population in St Helens, dementia is likely to be a significant ongoing health and social care issue.

Projections from Projecting Older People Population Information (POPPI) suggests that the number of people with dementia will continue to rise. As of April 2013, the prevalence in St Helens was 0.7%, with a total number of 1,297 people diagnosed with dementia, with a forecast of it rising to 2506 in 2020 (POPPI 2013). It is recognised that early detection of dementia can improve the outcomes for the patient, as well as it being cost effective. Research in the NHS found that each patient with Alzheimer's disease who received early assessment and treatment saved society £7,741, compared with a patient who hadn't. Improving awareness should help to improve the number of people who have a formal diagnosis of dementia, as currently it is estimated that 69% people with condition is formally diagnosed. This is likely to increase with raised awareness. At the end of June 2013, 1476 service users and carers have access to a dementia care adviser.

## Overview of current services

There 10 residential homes and 5 nursing homes in St Helens that specialise in providing care for people with dementia. These homes also offer respite care for people with dementia.

There are several types of services and support in the community for people with dementia, including but not limited to the Dementia Advisory Service (provided by Alzheimer's Society), Kershaw Day Centre, St Helens Carer's Centre, Age UK Mid-Mersey, St Helens MIND, Dementia Links, Disability Advice St Helens, the Pilkington Family Trust.

There are also Dementia Cafes at the Mansion House, St Marks Centre, Haydock, Tartan Tea Rooms, Rainford and Ashtons Green Community Allotments in Parr where there is also a gardening project. The Hargreaves Trust is another charity which offers support.

Other services which offer peer support is Looking Forward group supported by Senior Voice, Making Sense group at Peasley Cross, Broadoak Manor Carers Support group, 5 Boroughs Partnership Later Life and Memory Services Forum.

Local authority designated provision for people with dementia is available at Seddon Court. People with dementia can also reside at the other 4 extra care schemes in the Borough. These are Heyeswood in Haydock, Heald Farm Court in Earlestown, Reeve Court in Nutgrove and Parr Mount in Parr.

## Methods Used

### **The information pack.**

The information packs consisted of the following:

- Information on condition, food mood, driving
- Advice on contacting DVLA
- Lasting Power of Attorney
- Attendance Allowance etc.
- Information on MIND, Age UK, Hargreaves Trust etc and the activities they offer.
- Sample notice saying 'no cold callers'
- Contact numbers
- Information and contact for Carers
- PALS (Patient Advice Liaison Service)
- EDT (Emergency Duty Team)
- Cognitive function clinic leaflet (vascular)

All information was enclosed within a brown envelope with a stapled note on the front labelled Alzheimer's disease and vascular dementia, though they were virtually the same.

The questionnaire was devised and agreed by Healthwatch dementia task group and distributed electronically to the groups indicated above, to care homes, SIN network, and Borough Forum. (Please see appendix for questionnaire)

## Your Voice / The findings of our work

A total of 8 questionnaires were completed and returned within a 3 week timeframe. These were completed by Carers.

Generally they thought the quality of the packs were good as the rating average was 4.5 out of 5. However one person rated it as 1 as her own pack was incomplete. One carer felt it didn't relate to him and from the answers in his questionnaire, he really wanted someone to help him understand the condition his wife was facing and know what to do rather than have written information in front of him. Tony Boote – the Dementia Adviser from the Alzheimer's Society was considered to be most helpful in this situation.

Packs were seen as easy to read, attractive and informative. One person commented on the poor quality of photocopied leaflets as they were too dark to read. Another carer felt that there was lots of information in lots of leaflets, and there were too many booklets. She felt that the information should be coordinated even though she gave a high rating for the pack. The leaflet on support groups and activity timetables were out of date, and changes were not noted.

Another highlighted comment was that Picks disease – another form of dementia - was not sufficiently included.

One Carer whose mother was diagnosed two and a half years ago and treated by Mossley Hill Hospital in Liverpool was given an information pack with poor quality photocopying. When her mother moved to St Helens to be cared for, the Carer joined Age UK and received a booklet which she described as 'good quality with an excellent collection of leaflets, and a clear personal explanation by the Age UK Social Worker, as well as receiving excellent support from Social Services.

Six out of eight found the information 'just right' while the other 2 found it insufficient due to an inadequately stocked pack, and secondly one Carer felt it didn't relate to him. People received the information pack either at the Alzheimer's Society or Memory Clinic – this could have been a joint presentation to carers. Another Carer received it on a home visit.

Comments on 'what did people need most at point of diagnosis' was advice and personal support. One carer said 'he needed time to think. This reflected comments made in previous listening events of 2010 and 2011, that people were overwhelmed by the diagnosis and information at the beginning.

The people who received a Carer's assessment got support as a result, - one lady was able to get her own health issues sorted more quickly through support from the Carers Centre. Another lady received support when her Mother came to live with her and she was assessed.

Only 1 person had experience of an iPad being used and 'wasn't happy about it'. At the Carers Centre, none of the people spoken to had any experience of iPad use in assessment process and some carers felt it would have caused anxiety or further confusion if it had have been suggested.

The main contact for the Carers were Tony and Denise from the Alzheimer's Society, and the Carer's Centre. These organisations play a pivotal role in helping people to manage living with dementia by employing advisers and support workers. The carer whose mother lives with her has 3 other contacts details for St Helens Contact Centre, GP's 24 hour emergency respite, and a 24 hour emergency number for the Memory Clinic. She also felt supported as a Carer once her Mum came over from Liverpool to live with her. This indicates the level of support increases if the person with dementia lives with the Carer more than if they remained living at home alone.

One final comment made was that the GP/Nurse never ask the carer how they are coping with caring for the person with dementia, presumably this is if they go to the GP with something else. It is a well known fact that carers mental health and well-being often suffers as a result.

### **Carer's Centre feedback**

Included in the findings are comments sent in by the Carers Centre when asking Carers on an ad hoc basis how they felt about the information pack and iPads. The people asked (approx 30) included Carers who have supported someone through this process very recently and also within last 2 years.

'None of the people spoken to had any experience of iPad use in assessment process and some carers felt it would have caused anxiety or further confusion if it had have been suggested.

The information packs were felt to contain too much information and most carers felt that it was not relevant to their situation. I asked for an example of this and it was suggested that details of day care provision were not appropriate when someone has been very recently diagnosed.

Verbal prompts from staff at the clinic about Power of Attorney and potential benefits such as Attendance Allowance, DLA, Carers Allowance, Council tax reductions etc were thought to be helpful with signposting to relevant agencies who can offer support with this. One person felt that they needed more detailed explanation of medication and thought this would have been included within pack.

Overall carers reflected that packs were generally discarded so wonder if condensed version would be an option as sure it is still useful for people to have something to refer to after their consultation?'

## Conclusions

- The information packs are considered good quality but information needs to be coordinated in a better way with the avoidance of poorly photocopied literature. As highlighted above – maybe consider a condensed version of information as another option.
- Explanation on the information packs helps at a time that is appropriate to take in and digest the information.
- The information packs alone are not enough but in addition to the practical and emotional support for those people with Dementia and their Carers. The supporting roles provided by the Alzheimers Society, Age UK Mid Mersey and the Carers centre are very much valued, as they offer ‘the personal touch’
- There is insufficient comment provided on the use of iPads for supporting a referral for diagnosis to draw any real conclusions.

## Recommendations

Recommendation 1	Person/s involved	Timescale
<ul style="list-style-type: none"> <li>• Information within the pack needs to be coordinated – perhaps a flowchart to illustrate the pathway and services and refer to the relevant leaflet in the pack</li> <li>• A condensed format of the pack as an alternative option, and having 1 pack instead of 2 separate ones.</li> <li>• To ensure the information is up-to-date including dates, times and venues for activities, and contact details.</li> <li>• Information on Picks disease was suggested</li> <li>• Avoid badly photocopied leaflets</li> <li>• Highlight emergency numbers on the front of the pack so it is easy to access</li> <li>• Ensure that someone sits with the Carer/Patient to go through the pack with them at an appropriate time.</li> </ul>	<p>Healthwatch to take the Lead</p> <p>Alison Kenyon – LLAMS, 5BP</p> <p>Mandy Gough – Alzheimers Society</p>	<p>6 months 21/11/14</p>

Recommendation 2	Person/s involved	Timescale
To highlight on Carer's medical notes that they are a Carer for someone with dementia (if they are not already), so they can ask how they are coping. There is a Government initiative which encourages GPs to look out for signs of mental stress in Carers generally).	Alan Ashton - Carers Centre Katie Power - CCG	Need negotiation with Practice staff

## Action taken /feedback on recommendation 1

### a) Specifically to the information pack

The Memory Service Team feel that putting all the information together is too much to take in and could be perceived as confusing following a diagnosis. The Team plan to:

- Develop a flow chart to illustrate the pathway and services
- A new pack for Lewy Body is to be put together. However Picks disease is very rare therefore information will be provided on an individual basis
- The Memory Service Manager has requested that a support worker attends each clinic session to ensure the appropriate pack is given out and the contents are discussed with the Service User /Carer.
- The Manager has identified a staff member to monitor the quality if the pack regarding photocopying and up to date information.

### b) Ensure that someone sits with the Carer/Patient to go through the pack with them at an appropriate time.

The carer / patient being given the pack at the point of diagnosis cannot be changed as this is in accordance with NICE and CQC standards. Reasons for this is that this may be the only time the patient /carer is seen and might not access the service again, regardless of whether the information is too overwhelming at the time.

The LLAMS team make a referral to the Dementia Adviser Service the Dementia Adviser (DA) will sit with the person with dementia (and the carer and extended family if required) and go through whatever information they feel they need to know about. The DA will go out as many times as the family want throughout their journey; as their symptoms change. So although the LLAMS team are not able to sit with them that is what the Dementia Adviser Service is there for.

## Action taken / feedback on recommendation 2

- a) Highlighting 'carer' on the medical notes and general support.

The carers Centre has a GP Liaison Worker who has contact with all 45 GPs surgeries in the Borough, and as a result the following work has taken place and is continuous. There is / are:

- i) Ongoing Carers Awareness training for all staff within surgeries.
- ii) A designated Carers Champion in each surgery. This can vary on who it is.
- iii) A prescription notebook has been provided to all GPs, to make a referral to the Carers Centre. Each pad has a GP's ID number, and is identified when the referral is returned.
- iv) A system across all GP's surgeries where the patient who is a Carer is flagged up on the medical records
- v) Carers Emergency cards are issued once registered through the Carers Centre due to needing names and contact details of the carer, who is given a red card; and the cared-for person who is given a green card.
- vi) A Carers Centre own information pack which is the equivalent of 4 sided A4 sheets which is put into the form of a 4-fold leaflet. This is very condensed and easily accessible information, with a list of phone numbers for support. They are not involved with the LLAMS / Alzheimer's pack above.
- vii) Mental health support workers who liaise with the Alzheimer's society and attend their dementia support group meetings twice a month to provide support to carers.
- viii) A number of Healthwatch volunteers agreed to survey local GP surgeries to assess the level of information displayed about dementia and support for carers. There were mixed results of displayed information and Healthwatch will feed this back to the CCG for further action and improvement.

## Acknowledgements

Thanks to:

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Mandy Gough – Alzheimer’s Society  
Joanne Hornby – St Helens Carers Centre  
John Kelly – Looking Forward Group  
Tish Mckee - Dementia Links  
Kym Smith – Age UK Mid Mersey  
Tony Boote – Alzheimers Society  
Denise Adamson – Alzheimers Society  
Sandra Keatley – Crossroads Care (NW)  
Alison Kenyon – 5 Boroughs Partnership Trust  
Alan Ashton – Carers Centre  
Lindsay Martindale – Carers Centre  
Steve Ashton – Carers Centre

And to the Later Life and Memory Service Team

Special thanks to all carers who completed the questionnaire.

## Appendix 1

### Questionnaire

1. Are you someone with dementia or a carer of someone with dementia?  
Please state.
2. What do you think of the quality of the packs? Please comment.
3. Did you think the information was: (please circle)  
a) too much                      b) not enough                      c) just right
4. Was there anything in the pack which was not included, which should have been?
5. On a scale of 1-5 - 1 being the least useful to 5 being the most useful – how do you rate the pack?
6. At what point did you get given the information pack? Please circle.  

GP	Memory Clinic	Psychiatrist	Hospital
Alzheimer's Society		Carers Centre	Other (please state)
7. What did you most need at the time immediately after the diagnosis?
8. Has your carer or you (if you are a carer) had an assessment?
9. If so, did the carer receive more support as a result of the assessment?
10. Do you have a main person or organisation you can contact, should you need help in coping with dementia either as a carer or person with dementia? If so, please state.
11. **Only if this applies to you.**  
What did you think about your GP/Nurse asking you questions using the hand-held computer as an indicator for dementia? (iPad)
12. Anything comments or anything else you would like to tell us regarding the above questions?

## Appendix 2

### Questions relevant to the HWBB dementia project group - second action plan

<b>Phase 1 – When memory problems have prompted me and/or my carers/family to approach my GP with concerns</b>
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#### **Priority (New) Area/Action: GPs using screening tool (as at July 1013):**

All 37 GPs surgeries have dementia screening 'Ipad' apps. All practices have had training to use the screening tool and have been using it for 1 month. Screening levels and prevalence rates should increase. Data reported July 2013 - referrals have actually increased by 25 people per month for the last 2 months (5BP)

#### **Questions from Healthwatch task group**

1. How many of the 37 GPs are actually using this, some will be less inclined to use technology? Are there more referrals coming from certain surgeries?
2. What about the reliability of the app? Are traditional observations being omitted / is the app an additional tool or the sole determinant of diagnosis?
3. Does 5BP think that the increase in referrals is due to the ease of making an accurate referral for diagnosis due to the ipad or is it that 5BP have been promoting the LLAMS new way of working now being rolled out across the whole of 5BP? Or is it that the assessment team is now open later in the day (till 6pm or later) so that GP and self-referrals get through first time?
4. Are there other referral routes that are also increasing in referrals?
5. Are there different waiting times depending on whether e.g. a social worker refers suspecting dementia, etc.
6. If referrals are increasing, are these within the planned work (commissioner-agreed)? What happens when referrals go over the projected amount that commissioners have agreed?
7. Are referrals in line with population estimates, or does St. Helens have an additional amount of people coming forward due to local promotion and disease load – POPPI data suggests we have more incidence of dementia that you might expect.
8. Do GPs assess for alcohol use or substance misuse alongside dementia? What proportion of the patients are regular users? (Relates to other HWB strategy priorities)
9. Assuming that the GP has investigated other possible causes of the loss of memory, or if not, do the memory clinic themselves perform any physical tests? Is the information from the GP passed on to the memory clinic when the referral is made for further assessment?
10. How many people/what proportion is referred back to their GP because they don't have dementia or are screened out before memory clinic assessment?
11. Does 5BP investigate which GPs are not referring i.e. by tracing back patients that have clearly had symptoms for a while and are therefore advanced when they get assessed?

**Priority Area: Information and Guidance** – information continues to be refreshed and provided in GPs surgeries.

### Questions from Healthwatch task group

12. How could this be monitored – currently an action tasked to LINK/Healthwatch? Suggest that Healthwatch creates a checklist, Dementia project group members will need to approve this, and then Healthwatch members (initially task group and Friends of) asked to visit their own surgery and send in their findings.

13. An audio version of the basic information & guidance can be done via Healthwatch contacts (will help to reach people with literacy issues). Which organisation can resource this cost?

## Phase 2 – Learning that the condition is dementia

**Priority Area - Assessment Care and Treatment** – analysis of ACTS performance data and carer's support. Performance report of ACTS from 5BP is due imminently.

### Questions from Healthwatch task group

1. After an initial diagnosis, i.e. after first visit by assessor, what are the next steps?
2. How long from referrals to appointment at memory clinic? Advised that the time taken from referral to first appointment/session at the memory clinic is 10 days.
3. How and what does the memory clinic report back to the patients GP?
4. Does the memory clinic get in touch with a social worker, is this routine or not? Or is this the responsibility of the client (carer)?
5. If not at initial assessment stage, how often is the need for a social worker revisited?
6. When does the dementia adviser become involved – does memory clinic provide information in every case?
7. What happens to the people that aren't ready for memory clinics or treatment, do they get referred onto any other support services if 5BP does not accept the referral? N.B. Carer support is a major problem in these case, they can feel abandoned (and fear of the unknown) ...
8. What happens to people with early onset dementia that allegedly cannot access the service unless they are 65 or older? Any support given or referral to Dementia Care Advisor? (Third-hand evidence of a 63 yr old being told they were too young for their GP to refer them).
9. The Dementia Care Advisor is receiving 15 new referrals a month, and never receives any from GPs... is there a reason for this?
10. Can 5BP determine which GPs are not referring i.e. by tracing back patients that have clearly had symptoms for a while and are very advanced when they get assessed? Who has the remit to raise awareness with GPs, when there will be limits on what is commissioned and manageable?

11. How does 5BP support the patient apart from the memory clinic and/or medication, e.g. do they refer to... e.g. dementia cafes or Alzheimer's support groups? If not why not?
12. When does the carer of the patient get informed there is help and assistance available?
13. Is there a robust system supporting the carer when diagnosis is confirmed?
  - a. Where are carers involved in the assessment and care planning process? (Implementation of good practice 'Triangle of care')
  - b. Can 5BP identify the points in the patient's pathway where carers get support, and appropriate signposting and information?
  - c. Is there an information pack specifically for carers of people with dementia at Peasley Cross?
  - d. At what point are carers referred for a carer's assessment? This is the council's responsibility to provide (Carers Equality's Act 2004).
  - e. Are there any carers champions on the assessment or inpatient wards? How are they identified to the public – poster with photo etc?

<b>Phase 3 - Learning more about the disease, options for treatment and care, self management and support for me/family/carers.</b>
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**Priority Area: Dementia Care Advisor.** Dementia Care Advisor has received 330+ referrals from 1500 people that have been assessed (in first year of work). Approx. 1/3 have dementia, 2/3 are carers.

**Questions from Healthwatch task group**

1. Is this service sustainable? Does this show the need for another adviser?

**Priority Area: Training and Awareness-raising.** This has taken place across a wide range of agencies via the Care Homes Project and Alzheimer's Society/Bridgewater.

**Questions from Healthwatch task group**

2. What, if any evaluations have been done on this (we recognise it may be too early to see a significant impact). Care homes project independent evaluation in draft will be available in Autumn 2013.
3. Awareness raising and coping strategies for carers (training) – which organisation delivers this in St. Helens? (in Halton – 'Next Steps' - is delivered by Alzheimer's Society and the Brooker Centre). Healthwatch could promote this in future, but needs details and dates when it will be available, needs to be a rolling programme.
4. Has the carers Centre noticed a change in referrals from GP practices since the pilot for referrals from practices has ended? How can Healthwatch support practices to continue to

make referrals and monitor notice board information (see Phase 1, Priority Area: Information and Guidance)

**Priority Area - Peer Support.** 'Living well with Dementia' Support Groups have increased

**Questions from Healthwatch task group**

5. Is the current amount of groups enough? What about those/their carers awaiting diagnosis who will need support in the near future?

**Priority Area – Personal budgets**

**Questions from Healthwatch task group**

5. How is it intended to develop this area for people with dementia? Healthwatch could assist with a stakeholder analysis of who may need to be involved in this area.

<b>Phase 4 – Getting the right help and the right time, prevent crisis etc.</b>
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**Priority Area – Emergency contacts**

**Questions from Healthwatch task group**

1. Emergency cards (part of Carers' tender) and availability of Dementia /Mental health Support Worker (based at Halton Carers Centre) would improve support and signposting/advocacy available. Does the Dementia Care Advisor perform this role? Are there other dementia-specific measures that the Carers Centre is responsible for delivering (as part of the tender contract)?

2. Are carers getting appropriate support / do they know what to do in a crisis?

3. How well used is the literature on dementia at Carers Centre? Should it stay there or should it be distributed?

4. How is carers' respite breaks promoted to carers of people with dementia? Does the local authority officer responsible for the carers assessment function promote availability of carers respite?

5. At what point does 'someone' involve a social worker – whose remit is this? We assume this is only done when relevant needs present – what would the criteria be to involve a social worker?

**General point – Healthwatch St. Helens will create a simple flow-chart pathway showing the steps involved from phase 1 to phase 6, indicating where support might become relevant, which can be used if wished by all partners of the dementia project group.**

**If this is acceptable, this needs to become a new priority area under Phase 4.**

## **Phase 5 – Getting help if hospital care is needed**

### **Priority Area – Residential/Nursing, respite & permanent**

#### **Questions from Healthwatch task group**

1. What is the process to access an admission to hospital when care in a home is no longer feasible? Anecdotally people tell Healthwatch this only happens in a crisis situation. Need to make the way it is accessed more transparent.

### **Priority Area - Review of domiciliary care for people with dementia.**

#### **Questions from Healthwatch task group**

2. Report on general views of domiciliary care by LINK is in draft form awaiting Adult Services comments. Healthwatch would be able to assist with this review

## **Phase 6 – receiving care, compassion and support at the end of life**

### **Priority Area – End of Life Awareness Raising**

#### **Questions from Healthwatch task group**

1. When does the advanced care planning team become involved and who signposts to them? This information is needed by Healthwatch and other bodies to ensure the carer knows when they might contact them in the pathway and needs including in various ways and at a number of stages.

2. Healthwatch has previously agreed to assemble packs for carers re. End of Life planning including legal information. This is still an intention, but will need financing. Where will this resource come from?

3. Care homes will do assessment of a person's needs, including those identified in practices as the 1% likely to die within 12 months. What discussions are had, and whose role within the care home is it, to talk with residents and/or family members about end of life planning and e.g. Preferred Place of Care (at time of death), Do Not Attempt Resuscitation/CPR, etc.?