



Health & Community  
Directorate

*Scrutiny Review of Services in Halton for  
Younger Adults with Dementia*

May 2009

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## **1.0 Purpose of the Report**

1.1 This Report describes the issues and findings arising from a Health Scrutiny Committee Work Topic, set up to examine the services and supports available in Halton for younger adults with dementia. As described in the initial Topic Brief, the key outputs and outcomes were:

- A full and detailed analysis of the current extent of the development of dementia amongst younger adults in Halton
- An understanding of the extent of future need in Halton, informed by local, national and international research
- To establish whether there are any preventive or early intervention approaches that could reduce the burden and impact of these conditions on local residents
- An analysis of national best practice and the extent to which this can be delivered locally
- An agreed commissioning plan across all key stakeholders for this group of people
- The development of support networks for carers and families of people affected by these conditions

## **2.0 Structure of the Report**

2.1 The introduction to this Report explains the reason why the work topic took place. It is followed by a brief discussion of the process that the Work Topic Group took in gathering information and evidence. This is followed by a brief section on national and local policy drivers, and by some data about local prevalence. The Report ends with analysis, consideration of local issues and recommendations. The annexes include the topic brief and a personal account written by a carer of a younger adult with dementia.

## **3.0 Introduction:**

### **3.1 Reasons why the Work Topic took place**

3.1.1 In 2007, there was a small but noticeable increase in the numbers of people who were being referred for social care support who were under 65 years of age and were presenting with symptoms of dementia. From an average referral rate of two or three annually to mental health services, this had risen to around 13 in 2007.

3.1.2 This rise in referrals was matched by a pressure on the existing budget. Anecdotally, it seemed that people were being referred for support at a fairly late stage in their conditions, and as a result of this residential care became a more likely option. Specialist residential services for younger adults with dementia were not available in the Borough, with the result that placements in other areas had to be

found on occasion. These placements were frequently substantially more expensive than residential care for older people with dementia, and also had the effect of removing people from their families and local contacts.

### 3.2 **Membership of the Topic Team:**

3.2.1 The membership of the Topic Team included:

<b>Members</b>	<b>Officers</b>
Cllr Ellen Cargill – Chair Cllr Dave Austin Cllr Robert Gilligan Cllr Martha Lloyd Jones Cllr Joan Lowe Cllr Geoffrey Swift Cllr Pamela Wallace	Lindsay Smith – Divisional Manager, Mental Health Martin Loughna – Service Development Officer Kevin Holland – Team Support

### 3.3 **Methodology:**

3.1 This Scrutiny Review was conducted in a variety of ways:

- Meetings of the Work Topic Group, which included presentations from local experts working with younger adults with dementia
- Collation of “snapshot” data about local prevalence and costs
- One members’ visit
- A meeting by Members and an Officer with two carers and one person with early onset dementia
- Review of national and local policy guidance
- Review of information available on the internet

## 4 **National and Local Strategic Drivers**

### 4.1 The National Dementia Strategy:

4.1.1 This Strategy was launched in early 2009. It outlines three key areas to improve the quality of life for people with dementia and their carers, as follows:

4.1.2 *Improved awareness:* a general lack of awareness and understanding of dementia means that people are less likely to seek a diagnosis, and therefore do not access the help and support they need. The aim therefore is raise awareness amongst the public and professionals in order to develop a better understanding of dementia, so that people can access help and treatment at an earlier stage in their illness. This would include health promotion messages about the importance of good health and diet, as up to 50% of dementia generally is

attributable to vascular causes.

4.1.3 *Early diagnosis and support:* only a third of people with dementia receive a diagnosis at an early stage. There is substantial evidence that early diagnosis and treatment has better outcomes for people in terms of their quality of life, and it can delay or prevent unnecessary admissions into care homes. This approach is cost effective but would require initial investment.

4.1.4 *Living well with dementia:* two thirds of all people with dementia live in their own homes in the community. The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them. Services need to be flexible and reliable, ranging from early intervention to intensive specialist support. The care of people with dementia who are in general hospitals needs to be improved, and there is a particular emphasis on providing the right support for carers of people with dementia.

4.1.5 The strategy also addresses the issues in relation to improved quality of life for people in care homes, including the need for leadership, defined care pathways, and the provision of specialist in reach services. In addition there is a need to improve the quality of direct care provision in care homes including; nutrition, activities and social inclusion.

#### 4.2 Local response to the National Dementia Strategy:

4.2.1 An implementation plan is being developed, which includes the establishment of a local dementia strategy for Halton, across health, social care and private and voluntary sector services. This is currently being produced and should be available by the summer of 2009. Currently, this does not include consideration of the specific needs of younger adults with dementia.

4.2.2 Apart from the development of a local strategy, the implementation plan addresses the recommendations arising from the national strategy. This includes:

- Completing a financial impact assessment and identifying resource requirements
- Improving public and professional awareness of dementia
- Providing good quality early diagnosis and intervention
- Providing good quality information, and easy access to care and advice following diagnosis
- Improving community personal support services and intermediate care
- Improving the quality of care of people with dementia in general hospitals
- Implementing the carers strategy for carers of people with dementia

- Improved care in residential homes
- Improved end of life care for people with dementia
- A better trained workforce
- The development of a formal joint commissioning strategy for dementia
- Improved assessment of people with dementia

#### 4.3 Draft 4Boroughs Older People's Mental Health Strategy:

4.3.1 This strategy is being developed by the 5BoroughsPartnership, but only covers the four Local Authority Areas of Halton, Warrington, St Helens and Knowsley.

4.3.2 The Strategy's aims are to:

- deliver a system of care that is effective, valued and person centred within a context of recovery, social inclusion and choice
- improve quality of life and promote independence
- focus "positive ageing"
- develop on primary and secondary prevention
- develop mental health promotion
- ensure better early intervention
- provide care closer to home

4.3.3 The Strategy is specifically for people aged over 65 and does not consider the specific needs of younger adults with dementia.

#### 4.4 **Recommendations:**

- (i) ***The draft dementia strategy for Halton should specifically consider the needs of younger adults with dementia***
- (ii) ***The 4Boroughs draft dementia should also be encouraged to consider how services for younger people with dementia are delivered in the context of overall dementia services***

#### 5.0 **National and Local Prevalence Data:**

##### 5.1 The National Picture:

5.1.1 There are currently around 570,000 people living in the United Kingdom with a diagnosis of dementia. National research suggests that the true figure – taking into account those people who have not been diagnosed – is likely to be one third higher, making an overall figure of around 750,000. 18,500 (less than 2%) of these people are under 65. In addition, it is expected that the national figures overall for dementia will double in the next thirty years, and it is therefore

reasonable to assume that the figures for those aged less than 65 will also double.

5.1.2 Dementia is not a single condition- it has a number of forms, and its causes and derivations also vary. For some people, there is an hereditary component to their condition; others have acquired it through alcohol abuse, head trauma or serious infections. For some adults with learning disability, there is an increased likelihood of dementia at a younger age as a result of this learning disability, and as the life expectancy of this group of people continues to improve, so the likelihood of dementia at a younger age also increases.

## 5.2 Dementia in Halton:

5.2.1 Overall, there are 1061 people living in Halton with a diagnosis of dementia. If the research suggesting an under-reporting of around one third is correct, then the real figure is likely to be more than 1400 people.

5.2.2 As part of this Work Topic, an attempt was made to gain a picture of the numbers of adults in Halton under the age of 65 with a diagnosis of dementia, by obtaining information from within the Health and Community Directorate of the Council, from Halton and St Helens PCT and from the 5BoroughsPartnership, the local specialist mental health Trust.

5.2.3 A completely accurate picture was difficult to get, mainly because issues of confidentiality made it hard to cross-check data from the different organisations, and no figures from the 5BoroughsPartnership were available.

5.2.4 Data provided from within the Health and Community Directorate in November 2008 showed that 22 individuals were receiving care and support from the Council, at a total annual cost of £300,000. There was no clear pattern as to the cause of the dementia in each of these people – four were people with severe alcohol problems, another four had dementia as a result of strokes, and there were one or two more specialist conditions. The rest were categorised more widely as having early onset dementia.

5.2.5 In addition, the Halton and St Helens Primary Care Trust identified three more people whose care and support was being fully funded by the health services, at an annual cost of just under £200,000. Clearly, both the PCT and the Council were dealing with people whose needs had become so great that they required some form of community or residential support, so there are a number of additional people who are not known to either service.

5.2.6 The 5BoroughsPartnership provides the specialist assessment and health management of people with dementia who cannot be managed

through primary care services. Many of the people known to the Council or the PCT are also therefore known to the 5BoroughsPartnership. Anecdotally, the view of the specialist Consultant dealing with dementia was that their service was dealing with around 30 – 35 people who had varying stages of the condition.

## **6.0 Issues considered by the Work Topic group:**

### **6.1 Introduction:**

6.1.1 This was an entirely new area of work for all of the members of the Work Topic group, Members and Officers alike. Although there is a substantial amount of literature about older people with dementia, it became clear that there was much less consistent evidence nationally about the needs of younger adults with dementia, apart from some scholarly articles and some scattered examples around the country of local service delivery.

6.1.2 Given this, the Group effectively started with a blank slate, and therefore considered a wide range of issues. These are discussed in more detail below, but broadly covered the following areas:

- How significant is the problem of younger adults with dementia in Halton?
- Is there something about Halton which may make people more prone to developing dementia at an early age?
- Does public health and such things as good diet have role in preventing or managing dementia?
- What are the specific needs and issues for younger adults with dementia, as compared with people who develop dementia in older age?
- What planning processes are in place for younger adults with dementia
- What services are there locally for younger adults with dementia, and are there any examples of good practice that could inform future service developments?
- What are the needs of carers of younger adults with dementia?

### **6.2 The extent of the problem of younger adults with dementia in Halton: are there any local factors which contribute to this?**

6.2.1 A snapshot of local activity data has been described in paragraphs 5.2.4 – 5.2.5, indicating a figure of 30-35 younger adults with dementia in Halton receiving care and support from health and social care services. This needs further work, in particular to identify the population known to the 5BoroughsPartnership, the local specialist health provider of dementia services. This should be included as part of the development of an overall joint commissioning strategy for dementia, arising from the Action Plan to deliver the recommendations of the National Dementia Strategy.



6.2.2 From the data snapshot, it was clear that there is no single type of dementia that predominates in Halton. There had been a sense that dementias relating to alcohol abuse and addiction were increasing locally, but this does not seem to be borne out by the evidence. Similarly, the evidence received by the Work Group, particularly from Dr Paula Hancock from the Brooker Unit, was that there are no specific local environmental factors that contribute to the condition.

6.2.3 So saying, it is known that there are some factors which relate to individuals which may predispose them to a higher risk of dementia. The Work Group heard evidence that:

- For some people with particular forms of learning disability, there is a significantly higher risk of early onset dementia. In recent years, the survival rate of people with these disabilities has significantly improved, both nationally and in Halton, and so it is inevitable that the incidence of dementia at a younger age in these groups will also increase. Services and commissioners need to monitor this, and planning for this needs to be included in learning disability commissioning plans
- Excessive use of alcohol raises the likelihood of a range of health conditions, which include specific alcohol-related dementias. Halton is known to have a significantly high level of alcohol use, as compared with other areas, with a resultant increased risk of dementia. The Work Group was concerned that more should be done to alert people – and particularly young people – to these risks through public health campaigns and programmes
- Similarly, the risks of vascular disease are substantially increased amongst people who are overweight or clinically obese. Vascular disease is itself a high risk factor for dementia. The Work Group again considered that this should be addressed within the public health and health promotion agenda

6.2.4 **Recommendations:**

- (i) ***A more detailed analysis of the numbers of younger adults with dementia, their needs and current services, should be conducted as part of the development of a joint commissioning strategy for dementia. This should include a full analysis of the current financial commitment for this group of people, to ensure that resources are used as efficiently and effectively as possible to achieve the best possible outcomes***
- (ii) ***Learning disability services should ensure that the needs of adults within their service who may be more susceptible to dementia at an early age are fully considered within commissioning plans***
- (iii) ***Local Public Health and Health Promotion services***

***should consider how to make people aware of the added risk of dementia arising from excessive alcohol use and poor diet. This should be particularly targeted at young people.***

6.3 Is there anything different about younger adults with dementia, compared with people who develop the condition in older life?

6.3.1 Dementia is a destructive and incurable condition which, at its worst, leaves people unable to manage even the simplest aspects of their care. It is commonly associated with old age (but is certainly not an inevitable consequence of ageing), and this is in itself one of the difficulties. Evidence suggests that younger people are unaware of the possibility of dementia and are reluctant to refer themselves. Even if they do refer themselves, they are less likely to be diagnosed quickly, because professionals can be more reluctant to attach this diagnosis to a younger person.

6.3.2 There was an understanding amongst the Work Group that, if people develop dementia at a younger age, then the prognosis was that people could deteriorate more quickly than with a later-onset condition. This was largely refuted by expert evidence, and may be more related to the fact of later diagnosis in the first place, as described above.

6.3.3 However, there are some other issues which make the experience of younger adults with dementia different to that of older people. In particular:

- There is greater likelihood that the person with the condition is a parent of younger children, and therefore there are significant impacts on family life
- There is also a potential economic impact on both the person with the condition and their family, as people may still be in employment and, without the condition, could reasonably have expected to be economically productive for some years to come
- Finally – and importantly – most services for people with dementia are set up for an older age group. Younger adults can be one, even two, generations younger than those receiving help and support around them. As a consequence they may have little in common with the other people. This is particularly important when considering residential or nursing placements for people in the later stages of their condition.

6.3.4 The Work Group therefore felt it important to stress that younger people with dementia have many needs which **can** be met from a general service for people with dementia. However, they may also have additional issues to consider, and dementia services need to be structured to take these into account.

### 6.3.5 **Recommendations:**

- (i) when establishing a new service for adults with dementia, or reviewing an existing service, commissioners should examine the service to see whether it is suitable for the needs of younger adults with dementia**
- (ii) existing services should be encouraged in 2009 to examine their own processes to evidence their suitability for younger adults with dementia**

### 6.4 Planning processes and services for younger adults with dementia:

6.4.1 There is currently no formal process for managing the developments in service that are needed for this group of people. They do not “fit” current commissioning structures, as they are too young to be considered for older age services, and do not have the type of mental illness that would specifically qualify them for adult mental health services.

6.4.2 As a result of this, they can find themselves being managed by a range of services, including mental health services, learning disability services and services for people with physical disabilities. These services themselves were established to support people with other needs, and they do not deal with younger adults with dementia frequently enough to develop an expertise or knowledge base in working with this group of people.

6.4.3 The main specialist health service for people with dementia is provided by the 5BoroughsPartnership NHS Trust. The Work Group was impressed by the information provided by one of the doctors in that service, Dr Paula Hancock, and it was clear that people with dementia were receiving a caring and knowledgeable service which made a difference to their lives.

However, this service does not have a specific focus on the additional needs of younger adults with dementia. When compared with other areas, there were general service gaps, which apply equally to all people with dementia:

- memory clinics – these are in place and are effective within the 5BoroughsPartnership, but they could helpfully be extended to meet the needs of particular areas and to have more of a community presence
- team approach: a range of professional approaches is needed to provide a comprehensive service for people with dementia. Apart from the input of a specialist psychiatric service, contributions are also needed from neuropsychologists, speech therapists and social workers
- community support services: Around the country there are few

examples of service provision for younger adults with dementia. There are some examples, however, of outreach services, which provide direct input into families and carers, and these seem to be well regarded. Locally, the Alzheimer's Society provides valuable support in Halton to families and people who have dementia, and the Work Group was of the opinion that this model should be promoted further

- crisis services: although crisis services do exist for older people with dementia, and can be accessed if needed by younger people, they are not designed to meet the additional needs of younger adults

6.4.4 Within the Council, there are no services specifically for younger adults with dementia, and such things as specialist residential services have to be purchased from outside the Borough, with additional disruption to the person themselves, as well as their families and carers. As already seen, services are currently structured and provided by age. There is a recognition of the potential to redesign services across health and social care, so that this barrier is not in place.

6.4.5 The Work Group was of the opinion that it is essential that services and commissioning processes are aligned to ensure that this group of people do not drop through the planning "net". Services should be established which correctly reflect people's needs and not be determined by an age barrier. These services should be able to develop an expertise in meeting the needs of this group of people

6.4.6 ***Recommendations:***

- (i) service commissioners and planners should develop an agreement as to the most effective care pathway for this group of people, and services should be designed to reflect this***
- (ii) service delivery and planning should be redesigned to reflect need rather than age***
- (iii) service commissioners should examine the potential for the establishment of a specific crisis service for younger adults with dementia***

6.5 Carers:

6.5.1 Members had a moving interview with two carers of younger adults with dementia, and one actual adult with the condition. One of the carers, JB, has since submitted a testimony which is attached as Annex 2 to this Report.

6.5.2 As with the planning arrangements for younger people with dementia, and the way that services are structured, there are limited services to meet the needs of carers of younger adults with dementia. Other

service areas have carers services which have been set up expressly for those service areas and which develop a level of expertise in the area.

6.5.3 The notable exception to this is the local branch of the Alzheimer's Society, which is well regarded by carers. This service, which is funded through a contract with Halton Borough Council, provides a single worker to act as a Family Support Service for people with dementia, which includes younger adults. A range of supports is provided, including advice, education, activity groups, a luncheon club, social outings and activity groups, including reminiscence, which has been shown to have a positive effect on people with dementia.

6.5.4 Members heard that there were some very good examples of professional staff and the interventions they provided. However, there were also anecdotal examples where staff clearly did not appreciate the issues facing younger adults with dementia, and they recommended that training should be available for these staff.

6.5.5 Carers felt that it would be helpful to have a centre, or group of centres, which people with dementia could attend to receive treatment and therapy, according to the progress of their condition. Although this does not necessarily follow the current thinking that services should be more community-based, the principles of this can be used to adapt existing services to more exactly meet people's needs.

6.5.6 **Recommendations:**

- (i) ***awareness-raising training should be made available for general staff who may deal with younger adults with dementia as part of their day to day work***
- (ii) ***as day services are redesigned to take a stronger community focus, care should be taken to ensure that community services and supports can provide an environment which meets the needs of younger adults with dementia. This should be considered as part of the dementia commissioning strategy.***

7.0 **Summary of Recommendations:**

7.1 Introduction:

7.1.1 Recommendations arising from the Work Topic are contained throughout this Report. This Section pulls all the recommendations together and provides a rationale for each of them.

- 7.2. Summary of recommendations and rationale:
- 7.2.1 **Recommendation 1:** *“The draft dementia strategy for Halton should specifically consider the needs of younger adults with dementia” (paragraph 4.4). Rationale: the Halton dementia strategy will be the key driver for creating service improvements for people with dementia in Halton. This Strategy will, as a result of the work of the Work Topic Group and this recommendation, be also responsible for leading the development of appropriate services and supports for younger adults with dementia.*
- 7.2.2 **Recommendation 2:** *“The 4Boroughs draft Dementia Strategy should also be encouraged to consider how services for younger people with dementia are delivered in the context of overall dementia services” (paragraph 4.4). Rationale: the 5BoroughsPartnership is responsible for delivering specialist secondary health care services for people with dementia, and has developed a draft Strategy (with four of the Boroughs it covers) to say how it will do this. This Strategy does not currently include the specific needs of younger adults with dementia. This recommendation ensures that the new Strategy will also consider the different needs of younger adults.*
- 7.2.3 **Recommendation 3:** *“A more detailed analysis of the numbers of younger adults with dementia, their needs and current services, should be conducted as part of the development of a joint commissioning strategy for dementia. This should include a full analysis of the current financial commitment for this group of people, to ensure that resources are used as efficiently and effectively as possible to achieve the best possible outcomes” (paragraph 6.2.4). Rationale: the Work Topic undertook a “snapshot” of the current numbers of younger adults with dementia. This was not able to include more detailed information from the 5BoroughsPartnership, and this needs to be included in order to form a more accurate picture of local need and service structure. In addition, this Recommendation ensures that the current financial and resource commitment is fully considered by Commissioners in both health and social care services, to ensure that it is used efficiently and effectively.*
- 7.2.4 **Recommendation 4:** *“Learning disability services should ensure that the needs of adults within their service who may be more susceptible to dementia at an early age are fully considered within commissioning plans” (paragraph 6.2.4). Rationale: the Work Topic Group heard that there are some people with specific forms of learning disability who are more prone to developing early-onset dementia, because of their condition. This is not currently considered as a part of learning disability commissioning and planning.*
- 7.2.5 **Recommendation 5:** *“Local Public Health and Health Promotion services should consider how to make people aware of the added risk of dementia arising from excessive alcohol use and poor diet. This*

*should be particularly targeted at young people” (paragraph 6.2.4). Rationale: the Work Topic Group was very concerned that there needs to be much wider public awareness of the increased risks of dementia arising from such things as alcohol misuse and poor diet. It was considered that investment in this public health area could do much to reduce the risks of dementia in the wider population.*

- 7.2.6 **Recommendation 6:** *“when establishing a new service for adults with dementia, or reviewing an existing service, commissioners should examine the service to see whether it is suitable for the needs of younger adults with dementia” (paragraph 6.3.5). Rationale: this recommendation is designed to ensure that service commissioners always consider the needs of younger adults with dementia in their planning processes.*
- 7.2.7 **Recommendation 7:** *“existing services should be encouraged in 2009 to examine their own processes to evidence their suitability for younger adults with dementia” (paragraph 6.3.5). Rationale: this takes the previous recommendation one step further and asks service providers to do the same critical review of their own service, to see whether they could do more to support the younger age group who have dementia. These two recommendations, taken together, would potentially increase the range and number of local services for this group of people.*
- 7.2.8 **Recommendation 8:** *“service commissioners and planners should develop an agreement as to the most effective care pathway for this group of people, and services should be designed to reflect this” (paragraph 6.4.6). Rationale: care pathways describe the types of services and supports a person could expect to receive, according to the stage of their condition, and how and when people would access those services. This needs to be fully developed for younger adults, who may have additional needs, as part of the overall Halton Dementia Strategy.*
- 7.2.9 **Recommendation 9:** *“service delivery and planning should be redesigned to reflect need rather than age” (paragraph 6.4.6). Rationale: at present, planning processes and service provision are often specifically age-related, rather than reflecting the continuing needs of people. This can create the kind of situation where people do not “fit” into eligibility criteria for services and support, and the Work Topic Group felt that this was the case for younger adults with dementia. In addition, staff who work in services which do not specifically have expertise in a particular issue do not have the opportunity to develop the necessary skills and knowledge base. This recommendation is intended to prompt services to consider their current structures and the potential for redesign, to the benefit of all who use the services.*

- 7.2.10 **Recommendation 10:** *“service commissioners should examine the potential for the establishment of a specific crisis service for younger adults with dementia” (paragraph 6.4.6).* Rationale: this was a theme that came out on a number of occasions from people who gave their views to the Work Topic. No recommendation is made as to how this type of service should be configured, with the expectation that this would be addressed as part of the Halton Dementia Strategy.
- 7.2.11 **Recommendation 11:** *“awareness-raising training should be made available for general staff who may deal with younger adults with dementia as part of their day to day work” (paragraph 6.5.6).* Rationale: the Work Topic Group was convinced that, although dementia may have very similar issues across all age groups, there are also specific additional issues which need to be considered when working with younger adults. There was also a strong emphasis on the need to diagnose and intervene in the condition at an early stage. Evidence from a number of people suggested that dementia in younger adults is not always recognised or considered, at least until a much later stage than in older people. This recommendation is intended to ensure that key staff – particularly those working in primary care services – are equipped with the skills and knowledge to manage the condition more effectively.
- 7.2.12 **Recommendation 12:** *“as day services are redesigned to take a stronger community focus, care should be taken to ensure that community services and supports can provide an environment which meets the needs of younger adults with dementia. This should be considered as part of the dementia commissioning strategy” (paragraph 6.5.6).* Rationale: the Work Topic felt strongly that there was a need for a “place” for younger adults to go, where they and their carers could receive the help and support they need. However the Group was also mindful of the move towards more locality- and community-based services, and therefore wanted this recommendation to reflect these issues.



## TOPIC BRIEF

<b>Topic Title:</b>	Services for younger adults with dementia
<b>Officer Lead:</b>	Lindsay Smith (Divisional Manager, Mental Health)
<b>Planned start date:</b>	July 2008
<b>Target PPB meeting:</b>	March 2009

### **Topic description and scope:**

To review the commissioning and service provision in Halton for younger adults (age under 65) who develop dementia, so as to establish an agreed approach and model across all key stakeholders.

### **Why was this topic chosen?**

In recent years there has been a noticeable increase in the number of younger adults in Halton requiring social care supports because they have developed some form of dementia, and particularly in dementias related to alcohol use. In general the prognosis for this group of people has not been good and they have required a considerable level of care and support. There are no specialist services for this group of people in Halton, no work has been done locally to map the extent of future need and currently there is no consistent commissioning approach to this condition. In addition there are no specific support networks for families and carers of people affected by these conditions.

This topic has a specific focus on the health needs of the local population and will therefore contribute significantly towards meeting the Council's key strategic priorities.

### **Key outputs and outcomes sought:**

- A full and detailed analysis of the current extent of the development of dementia amongst younger adults in Halton
- An understanding of the extent of future need in Halton, informed by local, national and international research
- To establish whether there are any preventive or early intervention approaches that could reduce the burden and impact of these conditions on local residents
- An analysis of national best practice and the extent to which this can be delivered locally
- An agreed commissioning plan across all key stakeholders for this group of people

- The development of support networks for carers and families of people affected by these conditions

**Which of Halton’s 5 strategic priorities are addressed by this topic, and the key objectives and improvement targets it will help to achieve:**

**A Healthy Halton:**

Key Objective A: to understand fully the causes of ill health in Halton and act together to improve the overall health and well-being of local people

Key Objective D: to reduce the burden of disease in Halton by concentrating on lowering the rates of cancer and heart disease, mental ill health and diabetes and addressing the health needs of older people.

**Nature of expected/desired PPB input:**

Member-led review of the needs of younger adults with dementia.

**Preferred Mode of operation:**

- Analysis of the extent of local need, involving all key stakeholders
- Review of local current provision for younger people with dementia
- Benchmarking with comparator local authorities and known areas of good practice
- Field visits to areas of best practice

**Agreed and signed by:**

**PPB chair** ..... **Officer** .....

**Date** ..... **Date** .....

### **My story – living with a young person with Parkinsons Disease and related dementia and how the Government and Local Council Services could help me by J B, wife and carer.**

I fell in love with my J, 41 years ago. We have been married for 36 years. He made me laugh and helped me so much to cope with my father who had suffered with mental illness for so many years before he committed suicide in 1975. Without my J, I don't think I would have survived. He always masks his own and my concerns with laughter. He says this is the best medicine, along with lots of love, hugs and kisses, but this doesn't always work for me.

J was raised by his Mother and Aunty Lily. Aunty Lily had Parkinsons Disease and we had sole care of Aunty Lily for about ten years following J's Mums death in 1987. She suffered with this disease for about 17 years, but showed no signs whatsoever of dementia. Perhaps this is why I am finding it so hard to cope with my J's illness.

J was diagnosed in 2004 with Parkinson's Disease, aged 58, He was diagnosed with dementia officially in 2007. They think it is Lewy body dementia. J doesn't tremor much like Aunty Lily did, and the poor mobility and the pain he is sometimes in because of muscle rigidity is much worse than she ever experienced. Looking back, I believe he had shown some symptoms of both illnesses for quite a few years prior to diagnosis. In fact it was when he turned 50 when his facial expressions; slowness of movement; lack of concentration; confusion and short term memory problems first started to appear, although slight. Life went on as normal. We used to joke about him forgetting instructions and getting his words mixed up, we put it down to old age, senior moments,

I can cope with his Parkinson's Disease, but it is the dementia symptoms, which appear not all the time and this is hard as sometimes you think he is 'putting it on'. The confusion, lack of concentration; occasional visual hallucinations, repetition and short term memory problems are hardest of all to handle and the most upsetting. My J, who was so full of life; so active; so handy to have around the house is now full of anxiety, frustration and lack of self esteem and confidence. He gets embarrassed when he gets his words mixed up; he tries hard to fight this with laughter. His jokes and actions are sometimes inappropriate and he annoys me with his constant need to touch. Why do I feel this way? I never used to. I love him so much, but I am so full of anger and hurt because this illness is taking him away from me slowly but surely.

J's illness fluctuates from day to day. Sometimes its hard to recognise that he has a problem, apart from his 'parky' facial expression, or slowness of movement, or that during conversation he loses his thread and starts to get his words mixed up, or he will forget how to use a screwdriver. Its also about his sequencing of tasks and concentration, remembering what he set out to

do. He has a fantastic sense of humour, thank goodness he hasn't lost this. His socialisation is intact enough to warrant him to be on his 'good behaviour' when we have visitors. He makes a real effort and can appear to be pretty normal. This infuriates me sometimes as I may have been struggling with his behavioural challenges for days. The key is to be there for a protracted period to understand this condition. It can never be the same when others are not the sole carer, because being the sole carer invades every minute of every day. The way J presents himself to one person can be completely different to another.

Then there is nothing more soul destroying to me when I receive some unsolicited advice, perhaps from a friend or family member who think they know better. My family constantly tell me that I am taking away J's independence by something I may have done or they say "you shouldn't talk in front of him like that; or you shouldn't say that". I want to say "give me some help, what do you know". They are not helping me; just upsetting me. I have to learn from my mistakes and sometimes I can't cope! I often feel so sensitised and vulnerable so even when friends and family are trying to be sympathetic to me, it sometimes grates and annoys me.

I know I need to be in the best of health and right frame of mind to deal with this terrible illness.. Techniques and understanding of this illness should be practised by all the family unit.

I suppose I am a bit 'gobby;. I am not afraid to ask for help. I have never been slow in coming forward and have always been very open and honest. We have a great GP, Dr V in the B Surgery in Widnes and J has a good Consultant, Dr F in the Walton Neuro Centre and Dr D in St J's Unit – they are simply the best! I also have the support of the Alzhiemers & Parkinsons Society and their websites. Thank goodness for L D and K from the Runcorn/Halton Alzhiemers Group, J N and B G from the Carers Support Group, L and B the Parkinson's Community Workers and the Parkinsons Specialist Nurses, I couldn't cope without them.

In Halton, the Support Services are great, but they can only do so much. There is a lack of funding and understanding by Government and Local Officials with regard to young people with dementia. I have had some bad experiences with Social Workers/Care Placement Officers, very nice people, but I believe they do not understand these illnesses and do not do their homework before offering services. I do think younger people with dementia are neglected, perhaps this is to do with a lack of knowledge on my part as to what is on offer, or maybe there is very little provision for them.

I believe anyone with a mental, or related illness, needs one to one help to begin with from professional specialist services and carers until they are accustomed to anywhere new never mind new faces. Are day centres/workshops and care in the community the answer? I am fortunate to remember a little of how individuals with a mental illness were treated in the past, and a lot we would not want to resurface, but there were some good things that happened. The use of therapists – occupational, speech and other

psychiatric therapists and specialist nurses were first-class. They had centres to accommodate the period that followed the 'in patient' spell when the patient was given the opportunity to get back into the community by re-educating them whilst still under the care of trained professionals'.

Whilst I appreciate the hard work the 'carers within the community' are giving, many may not be professionally trained. A suggestion I would make is why not have purpose built centres created to help and support the different stages of alzheimer sufferers that are led by professionals and specialist care assistants to support them. The early onset of dementia patient would perhaps benefit from speech therapists and physio, and therapists who could rebuild confidence and social skills. This part of the centre could provide related activities suited to their needs. So when a patient is first diagnosed they could attend the centre on a part-time basis; be assigned a care assistant who will eventually be taking them out into the community (the care assistant, with occasional visits from Social Workers, could learn a lot from the professionals during the sufferer's period at the centre, not only about the illness, but also of the sufferer's needs when going out into the community). There could be different parts of the purpose built centre to accommodate the other stages of alzhiemers that are suited to the needs of the various developmental stages of the disease.

In summary, a dedicated unit within the purpose built centre to support the needs of all alzhiemer sufferers at different stages of the disease. I realise this will require a lot of thought, planning and funding, but units like this will not only help to treat alzhiemer patients, but will provide the much needed respite for carers. Funding could come from the individual's DLA allowance, charity donations such as the lottery, together with funding from the government.

It's just my suggestion which I believe could support the Government's new strategy on dementia.