



## SHEFFIELD CITY COUNCIL Cabinet Report

**Report of:** Richard Webb, Executive Director Communities

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**Date:** 31/10/12

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**Subject:** Transforming Support for People with Dementia Living at Home in Sheffield- Report on the Involvement Exercise

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**Author of Report:** Howard Waddicor, Commissioning Officer

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### **Summary:**

- To inform some of the changes needed to modernise the support for people with dementia who live at home, a report was submitted to the Sheffield City Council Cabinet on 26<sup>th</sup> May 2012 seeking approval to engage in a three month involvement exercise.
- The purpose of the involvement exercise was to understand the key issues for people affected by dementia in order to plan support for the future. The growing number of people with dementia represents a significant issue for the city. The existing support arrangements will not meet the increase in demand or the changing expectations of people with dementia.
- This report:
  - Summarises the results of the involvement exercise
  - Makes a number of proposals for the way in which the council will invest in supporting people with dementia.
  - Describes how the Sheffield Health and Social Care Trust will further consult on the shape of its services
  - It also sets out the identified savings to be achieved.

### **Reasons for Recommendations**

- The responses to the involvement exercise summarised in this report identified some areas for improvement in the existing support arrangements for people with dementia and the need for change. It also highlighted practice changes which will help people to live well at home.
- The report recognises the need to ensure adequate investment in services to support people with dementia in the early stages and also for those people with complex needs.
- In addition it sets out the requirement to identify savings. It proposes to

achieve those savings through exploring the potential to reduce the number of buildings needed to deliver the service whilst maintaining the overall service levels.

- It sets out a plan for consultation on these proposals to be undertaken by the Sheffield Health and Social Care Trust.

### **Recommendations:**

(1) That Cabinet notes the outcome of the Involvement Exercise and in particular thanks the Alzheimer's Society for the production of the report on the views of people with dementia.

(2) That Cabinet acknowledges in the light of this that support for people with dementia needs to change.

(3) That Cabinet agrees to consult with people with dementia and their carers to on how services can be changed in the light of these findings and to achieve the required savings and asks the Sheffield Health and Social Care Trust to work with the City Council in this consultation exercise.

(4) That Cabinet agrees that the consultation exercise referred to in (3) above will include consulting on how alternative, and a wider range of, support and services, and the increased use of personal budgets could be developed to allow the potential closure of Norbury by the end of March 2013 and Bole Hill View by March 2014.

(5) That the Executive Director, Communities, be given delegated authority:-

(a) to finalise arrangements for carrying out the consultation exercise referred to in (3) above, including making appropriate arrangements with Sheffield Health and Social Care Trust; and

(b) to implement such changes to the provision of services for people with dementia as he shall consider appropriate, such authority to be exercised following the conclusion of the consultation exercise and having due regard to its outcome, and in consultation with the Cabinet Member for Health, Care and Independent Living, and further provided that all associated costs are covered by available budgets.

### **Background Papers:**

### **Category of Report:**

Open

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### Statutory and Council Policy Checklist

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|---|
| Financial implications  |
| Yes Cleared by: Karen Hesketh   |
| Legal implications  |
| YES Cleared by: Andrew Bullock  |
| Equality of Opportunity implications  |
| YES Cleared by: Bev Coukham   |
| Tackling Health Inequalities implications                                   |
| YES   |
| Human rights implications   |
| NO  |
| Environmental and Sustainability implications                               |
| YES   |
| Economic impact   |
| NO  |
| Community safety implications   |
| NO  |
| Human resources implications  |
| YES Cleared by  |
| Property implications   |
| YES   |
| Area(s) affected  |
| ALL   |
| Relevant Scrutiny Board if decision called in                               |
| Health and Community Care Scrutiny Committee                                |
| Is the item a matter which is reserved for approval by the City Council? NO |
|   |
| Press release   |
| YES   |

## **1.0 SUMMARY**

- 1.1 To inform some of the changes needed to modernise the support for people with dementia who live at home, a report was submitted to the Sheffield City Council Cabinet on 26<sup>th</sup> May 2012 seeking approval to engage in a three month involvement exercise.
- 1.2 The purpose of the involvement exercise was to understand the key issues for people affected by dementia in order to plan support for the future. The growing number of people with dementia represents a significant issue for the city. The existing support arrangements will not meet the increase in demand nor the changing expectations of people with dementia.
- 1.3 This report:
- Summarises the results of the involvement exercise
  - Makes a number of proposals for the way in which the council will invest in supporting people with dementia.
  - Describes how the Sheffield Health and Social Care Trust will further consult on the shape of its services
  - It also sets out the identified savings to be achieved.

## **2.0 HOW DID WE CONSULT?**

- 2.1 The exercise began on 1/6/2012 and finished on 31/8/2012. The key questions were:
- How can Sheffield communities better understand the needs of people with dementia so that living at home is a safe and positive option?
  - What types of support work best for people with dementia living at home?
  - What are the features of good support for carers of people with dementia?
  - How can we facilitate change but protect existing users of services?
  - How can health and social care providers work closer together for the benefit of people with dementia?
- 2.2 Responses were sought from:
- People with dementia
  - Carers of people with dementia
  - Providers of support
  - Community groups and organisations

- Other interested parties including NHS Sheffield, housing providers, the wider council and the voluntary community and faith sector

A range of activities were used to engage people:

- A carers' event was held on 31/7/12 at the Town Hall attended by over 50 carers. This has produced a significant amount of information, and a number of important suggestions and comments on how support should be delivered.
- On Tuesday 21/8/12 a 'Talk to Us' day was held at the Showcase Sheffield exhibition centre, a shop-front on the corner of Pinstone Street and Cambridge St. inviting responses from people who had not been able to make comments in other settings.
- Sheffield Alzheimer's Society has undertaken to work with a group of people with dementia and produced a report about their specific views.
- A postcard has been co-produced with carers inviting people to suggest ways in which Sheffield can lead the way in becoming a dementia friendly city by 2015 (see **Appendix A**)
- There have been specific meetings with a range of providers to invite comments from their perspective about how services should develop.
- A number of visits have also been made to carers who were unable to attend events
- All stakeholders have been invited to produce written responses to the 5 questions.

### **3.0 WHAT CARERS AND OTHER STAKEHOLDERS TOLD US**

3.1 To help understand what the responses mean for future investment in dementia services, representative contributions have been set out in **APPENDIX B** into the different levels of social care investment. These levels reflect the intensity and cost of delivering support. Broadly Levels 1 and 2 include those support services that help people (including carers) before they have an eligible social care need. Level 3a delivers support to people who live at home including specialist interventions. Level 3b is for those people in care homes.

3.2 In general the responses emphasise the need to increase investment in a wider range of support for people with dementia in the early and middle stages to make sure that people have the best chance of living well at home.

- 3.3 Through better support for people at home we should successfully delay, or prevent, the need to fund more expensive support for people in care homes. Currently this is by far the biggest proportion of funding. A relatively modest shift in the proportion of people supported at this level would similarly enable an increase in the proportion of funding available to ensure people are able to live well at home.
- 3.4 What came through very strongly was that whilst this shift can reduce admissions to care homes, support needs to be maintained for the relatively small proportion of people with the most complex needs at home. This refers to those people, some of whom are currently supported by the resource centres, who are most at risk of admission to a care home (Level 3a).
- 3.5 Key themes emerging included:

**Promoting lifelong health and wellbeing and early interventions that promote independence (Levels 1 and 2)**

- The importance of creating a **dementia-friendly city**. Whilst health and social care support is crucial to living well, people with dementia and their carers also live in communities which need to better understand the issues they face. This is particularly important in the early stages when people still want to do the things that they have always done.
- There is a clear view that there is **no single answer** to what is right for people with dementia. The experience of dementia and the resources each individual has to manage varies which means that a range of support opportunities is required.
- **Early diagnosis** is crucial and early access to support to help plan for the future is something most people recognise, often with hindsight, is valuable.
- There is too little **information** for people about what is available and what might help. It was also recognised that people need help understanding what the right kind of support is.
- Providing opportunities for **carers** to have a break – both planned and in a crisis – enables them to live

their own lives and be confident about the support offered to the person with dementia. In addition all those involved with the person with dementia need to understand the emotional impact on the carer and take time to acknowledge that.

### **Medium to long term care and support in the community (Level 3a)**

- Improving the way **health and social care** and other public services work together to support people to live at home can improve the experience of people with dementia. This applies especially to people with dementia discharged from hospital to make sure they are safe and that the levels of community support is adequate to sustain them.
- It was very clear that people with more **complex needs** should have access to the right amount of individualised support, using community resources, alongside an integrated range of more formal health and social care interventions. This was viewed as vital to reduce the likelihood of admission to a care home or hospital. The key message is that the support for this group should have the same personalised approach but be delivered by skilled staff in settings that are appropriate to their needs. Not everybody who was at this level was able to be supported through the existing resource centre model.
- **Home support** providers even specialist support, seem to lack the skills and understanding of how to support people with dementia. Particular concern was raised about those people who live alone.

### **Care in a care home (Level 3b)**

- **Care Homes** Though not specifically part of the exercise, views were expressed about the support that people have received in residential and nursing care. Though many found the support good there was evidence of inconsistencies and a lack of skill in supporting people with dementia – even in specialist units.

## 4.0 THE VIEWS OF PEOPLE WITH DEMENTIA

- 4.1 The response from people with dementia themselves is of particular value. It is the first time this has been attempted in Sheffield and is by no means the norm in other local authorities. The full report compiled by the Sheffield Alzheimer's Society on behalf of Sheffield City Council can be viewed at <https://www.sheffield.gov.uk/caresupport/policy/dementia-support.html>. The response contains the views of those people who were involved but also links to some conclusions that form part of Alzheimer's Society's overall response to the questions posed.
- 4.2 Part of this report is worth reproducing here in full as it says so much about the experience of people with dementia and their sense of powerlessness. *"An interesting artefact of this survey is that in the context of these interviews, many people talked about and considered services that they are likely to have rejected when raised within the context of an assessment for support. Many people expressed surprise, pleasure and approval at being asked their views in this study and it is a strong possibility that an increased sense of self esteem and confidence (due to being 'consulted') made it less threatening to consider support options. Assessment processes (the gateway to services) do tend to focus on problems, and can feel invasive and humiliating for the person with dementia. Assessment processes are often a deterrent to seeking services because it is known that the person with dementia will find them stressful"*
- 4.3 **Appendix D** is a fuller extract from the report which gives a direct response to the questions posed in the Involvement Exercise. The main points are:
- The importance to people with dementia of remaining in their own communities. This does not always translate into geographical communities rather "...a 'dementia community' where people have told us they feel understood, safe and able to get a great deal of informal support"
  - People with dementia want support from people who know about, understand and can help facilitate their involvement in wider social and support networks.
  - For people in this survey, day care and companion/carer type services have to be more than providing a break for their partner/supporter. They need to be an attractive option. For this to work for people with dementia, choice and control have to precede assessment
  - People spoke of their fear of having to go into a care



home, with several people becoming tearful in the interviews either talking about losing their partners, having to go into care or seeing a parent go into a care home. Care homes were still a dreaded ending for most people with one person stating that more money should be spent on providing support for families and less on care homes.

- Assessment processes need to be streamlined and sensitive to the particular fears and concerns people with dementia have to the disturbance to their sense of normality, self worth and autonomy. This would indicate that assessors need to have training in dementia awareness and person centred approaches.
- A strong message from this survey is that good and acceptable support for the person with dementia would be very valuable to the people who support them
- The commissioning and contracting of services should not interrupt successful services as perceived by the person with dementia. The considerations of continuity and familiarity should be paramount in any development or reconfiguration of services for people with dementia.
- All health and social care providers need to do much more consultation with people with dementia and make a genuine effort to integrate their perspectives into the commissioning, design and delivery of services intended to support them.

#### 4.4

In addition a number of comments about existing support as experienced by people with dementia were captured:

- Being normal and carrying on were themes set in a context of familiarity and security. People talked about the importance of home and feeling safe and settled in their own place. This was felt to be crucial to their ability to feel normal and carry on. Many people had lived in their current homes many years and their memories were tied up with a strong sense of place and home.
- By far the greatest amount of support and social contact people were getting was from their families. Nearly everyone in this study talked about the importance of the person who supported them most who was either their partner or a family member.
- Outside the family, people were involved in a great variety of groups and activities. Most of the groups and activities talked about were those provided by the Alzheimer's Society, (e.g., Cafés, Singing for the Brain, support groups, Walking group, Circle dancing) but there were also many people going to local clubs, and

activities/classes run by other organisations. One respondent said: *“Singing for the Brain...we’ve sung at places I never thought I’d do, feels good, achieving things like that still”*

- Although most of the people involved were not clear where paid carers who supported them at home came from, their opinion regarding these ‘carers’ was mostly positive.
- Not all those asked had attended day centres and the response was mixed. Some people valued the friendships and the activities, others were not sure: *‘something I can’t put my finger on....I just wasn’t comfortable there.’*
- When asked about groups and events where they, and the people who support them, could come together most people made very positive comments. Cafes, coach trips, walking groups, any group or event where the person with dementia could come with someone they knew was seen as the best and most acceptable type of support to them.

## **5.0 COMMENTS BY HEALTHIER COMMUNITIES AND ADULT SOCIAL CARE SCRUTINY COMMITTEE**

5.1 An initial report was taken on 12/9/12 to the Healthier Communities and Adult Social Care Scrutiny Committee based on the early findings of the Involvement Exercise.

5.2 Members made a number of comments:

- An integrated response to early intervention was strongly supported - they want to see an emphasis on the wider determinants of wellbeing being considered in the way that services are improved.
- Training/skills development across the statutory and independent sector was regarded as being extremely important and a request was made for this to be considered in the action plan.
- The waiting period for the memory service was still seen as a cause for concern.
- The self-directed support assessment process was highlighted as being too bureaucratic for people with dementia. They asked whether this could be simplified and was there the potential to introduce an advanced

decision making approach.

- The number of people in care homes without a formal diagnosis was seen as being inappropriate.
- A request was also made for further information about how the needs of people from BME communities were being responded to.

5.3 In relation to delays for the memory service this issue is being addressed by NHS Sheffield the commissioning body for the service. It is important to note that Sheffield has the third highest diagnosis rate for people with dementia in England and Wales and there has been a 50% increase in the capacity of the memory service.

5.4 In relation to care home residents not having formal diagnosis - the guidance we have given is that care home residents only need a formal diagnosis from the memory service if there is an advantage to knowing the type of dementia. An example would be the prescribing of medication to reduce the impact of the dementia.

## 6.0 **WHAT DOES THIS MEAN FOR THE FUTURE OF SUPPORT FOR PEOPLE WITH DEMENTIA?**

6.1 This involvement exercise has been successful in capturing a range of views about the future of dementia support in Sheffield. For the first time it brings together the views of both carers and people with dementia. The challenge in drawing conclusions from this is to make sure that the main themes are identified and appropriately prioritised.

6.2 It is unlikely that there will be universal agreement about what they mean – people are at different stages. Some carers' views, for example, may not always coincide with those of people with dementia. However, a number of important points are clear:

- Early intervention is vital. Linked to early diagnosis should be supported access to information about what the future will hold and what people can do to prepare for this.
- This includes capturing the views of the person themselves whilst they retain capacity so that support can be developed in a personalised way.
- There is no single solution to what works best which means that people should be supported to develop solutions that work for them. Before they require formal social care support this should include promoting

dementia friendly communities but also building up opportunities for people to be with others 'in the same boat' – a community of dementia.

- Investment should be focussed on making it possible for people to live at home as long as possible. The fear of admission to a care home is powerful for most people with dementia. Whilst for some this remains a successful outcome the greatest effort should be put on making it possible to live well at home.
- This is particularly relevant for people with the most complex needs. A key message is that the support for this group should have the same personalised approach but be delivered by skilled staff in settings that are appropriate to their needs. Many people in this group are supported by the existing resource centre model – but not all.
- There was almost total agreement that this group requires the same, if not increased, level of support if admission to care is to be avoided and carers are to also be able to live well.
- Understanding the needs of people with dementia and the people who care for them by those who work with them is vital. This applies to all staff supporting people with dementia at home as well as GPs and hospital staff.

## 7.0 HOW WILL THE COUNCIL ACHIEVE THE CHANGES NEEDED?

7.1 There are a number of key changes that need to be addressed:

- **More support for people around the time of diagnosis** and in the early stages – improved information advice and support
- **Increased investment** in preventative services that support people with dementia and their carers before they have a formal social care need to help them remain part of their communities
- Ensure an **integrated, flexible and personalised support for people with more complex needs** to reduce or delay the likelihood of admission to care

7.2 To achieve this in a context where the financial challenges are significant, and savings have to be made, the council proposes to work with partners to:

- Retain existing services to meet current needs but re-modelled to reflect the responses made in the involvement exercise

- Reduce the number of buildings used to deliver support
- Reinvest some of the money that this saves in developing community and home based support that reduces the need for long term care
- Use funds released from reduced admissions to care homes to increase capacity in community services as the numbers continue to grow.
- Use the remainder of the money to achieve the savings required for this service area

### **Retain existing services to meet current needs**

- 7.3 Critically, these changes would need to be achieved in a way that enables carers to have the same opportunity for a break as they currently do whether that is day support or respite care. Any reduction in support is likely to lead to an increase in admissions to care as carers feel no longer able to cope.
- 7.4 At the same time as developing new opportunities for people currently excluded from services we need to acknowledge that for some people the 'traditional' model of support is much appreciated. A radical move away from this model would not be experienced as positive by all people with dementia or their carers. Continuity was a theme emphasised by many respondents so any proposals for change should allow for the maintenance of this type of care as an option – especially for existing users. This should not preclude them from accessing other less formal opportunities.

### **Reduce the number of buildings used to deliver support**

- 7.5 The question most asked during the period of the Involvement Exercise was “will the dementia resource centres be closed?” The reason for this was the understandable fear that removing the support that the centres offer would be the final straw for many carers who are just about coping. They benefit from the support from that the staff at the centres offer and cannot imagine how anyone would want to close them.
- 7.6 It was also emphasised throughout the exercise that many staff – especially in the resource centres - have a high level of skill and empathy with both carers and people with dementia. Any proposals should ensure that this asset is not lost but rather used to greater advantage. UNISON, representing some of the staff in the resource centres, emphasised in their response that...” the dementia resource centres working in the city are essential in supporting clients and their carers on a number of levels but particularly are well placed to ensure that as many clients as possible are able to remain in their own homes or at

times of need or where there is carer stress or breakdown they allow a safe and speedy admissions process, high quality care and a rate of returning to people to their own homes which we do not believe anyone else could match”

- 7.7 There is no doubt that the centres do offer support to many people but not everybody is able to use them and some choose not to. Some people who had personal budgets chose to use other providers – particularly for respite care because they could get more for their personal budget from an independent sector provider – the difference can be as much as £300 per week. There is some evidence that relatively few people now use the centres for regular respite care and the beds are increasingly used for emergency places. That in itself is a reflection of the difficulties faced by carers and evidence of the need to improve the quantity and range of support.
- 7.8 It has been reported that some people who have sought respite from the independent sector have found that the provision was unable to meet their needs and they have returned to the resource centres. In general though, across all older people services, respite care has become less popular. The Council and other agencies in the city have worked together to develop an improved system of monitoring private and voluntary sector care homes. The Council is looking to further develop this by investing in the appointment of a post to work with others in improving care home practice.
- 7.9 For some people with dementia respite care can be disruptive. Nevertheless there is evidently still a demand for respite care but at a reduced level than required in previous years. If respite in resource centres is regarded as good but expensive then this support needs to be commissioned from another provider to a clear specification in terms of quality at a price which allows personal budgets to be used to better effect.
- 7.10 This would allow the resource centres to offer bed-based care in a crisis and expand the provision of support for people during the day. The proposals being considered by the city council and Sheffield Health and Social Care Trust include support for people who do not use the day services as currently offered. The proposals are expected to offer an increased level of service to those people including those with the most complex needs.
- 7.11 To enable this change to happen the Trust has worked with Sheffield City Council to consider how to reduce their dependence on buildings for the delivery of services. Plans have been developed that allow for support levels to be maintained but as part of a staged reduction in the buildings

used. It is therefore proposed to consider the closure of Norbury by the end of March 2013 and Bole Hill View by the end of March 2014. It is expected that by taking this step the Trust would be better placed to support the development of a range of services that fits with many of the comments made by people during the summer.

7.12 It is to be expected that some people will feel that this represents a loss of support. The link between buildings and support has been a key element of dementia support for some time. However, in order to allow the existing level of support to continue, accommodate a growing number of people with dementia, develop a more personalised service and achieve the savings required there appears to be little alternative to closing some buildings. However, it is also important to recognise that it is not the buildings themselves but the people who deliver the support that defines the experience for those who need support. Moreover, these centres are not providers of long term care. Whatever the significance of the centres in the lives of people who use them and their carers they are not where people live.

7.13 Further time is needed to consider these proposals and to consult and work with current users about what might be achieved. It is intended that this will give an opportunity for the model to be co-produced in the context of savings needing to be achieved.

### **Reinvesting in community and home based support**

7.14 To support this strategy additional investment is required in resources in the early stages based on the dementia café experience but extending this to provide a wider range of opportunities in different parts of the city, including exploring the potential for a dementia café with the Muslim and other BME communities. This would be an opportunity for people with dementia and carers to have direct input into the final shape of this support.

7.15 The involvement exercise underlined the benefits for some people with dementia of a personal budget. Based on their support plan people have been able to obtain flexible, tailored, and creative support for their on-going needs. This approach is now available to all people who have an eligible social care need. As it becomes the norm existing care providers will want to change their services to make them more attractive and relevant to people with dementia and their families. In the future this opportunity will be extended to include personal budgets that will cover both social and health needs.

- 17.6 The most vulnerable group are those people with dementia who live alone. This represents a particular challenge as there is a heightened sense of risk. For someone to live well at home in these circumstances requires all agencies to remain focussed on the wishes and feelings of the person themselves. In addition creativity in the use of assistive technology, as part a of support plan, working with neighbours, distant carers and others to understand and reduce the risk and support positive experiences.
- 7.17 In addition Sheffield City Council and NHS Sheffield Clinical Commissioning Group have already committed to commissioning a revised information, advice and support service to support people with dementia to make plans and access appropriate support.
- 7.18 The comments by Scrutiny, people with dementia and many other contributors about the assessment process are timely. The Care and Support service in Adult Social Care are already looking to adapt their procedures for the assessment to allow people to make choices at the right time with people who they trust. They are also introducing more streamlined processes but at the same time, emphasise its critical contribution in transforming support for people with dementia living at home.
- 7.19 In support of this Sheffield City Council and the NHS Sheffield Clinical Commissioning Group are also proposing to establish a project which will allow people with dementia to continue to guide the way services are commissioned and comment on their experience. This project will be part of an ambition to ensure that Sheffield becomes a truly dementia friendly city by 2015.
- 7.19 One of the key elements of the National Dementia Strategy is ensuring that all staff – wherever they work - understand their role in supporting people with dementia. In Sheffield as part of the Dementia Programme the council and health colleagues have identified where training gaps exist and have agreed plans for achieving the skills needed to support people with dementia in all settings. Good examples include the training for all Sanctuary housing staff, including repairs staff, which encourages them to identify people who are at risk and report their concerns.

### **Reduced admissions to care homes**

- 7.21 In the longer term savings delivered through reduced admissions to care homes will be used to expand the community services to cope with the expected growth in the numbers of people with dementia over the next five years



## **Achieving the savings**

7.22 Through this approach the city council believes in can achieve the required savings set out in Section 9

### **8.0 CONSULTATION ON THE PROPOSALS**

8.1 Sheffield City Council and Sheffield Health and Social Care Trust propose to work further to consider the options about the future of services. As a result of the involvement exercise they are now in a position to do this with a more detailed understanding of the views of people with dementia who may need their services in the future.

8.2 In the light of the extensive involvement exercise that has preceded this report it is intended to conclude the consultation by 31/1/13.

8.3 It is expected that this will involve existing users, where possible, and their carers in the design of services to ensure that they reflect their wishes but also allow any change to happen in a way that minimises the disruption to existing users.

8.4 This consultation will take place in the light of the Equality Impact Assessment set out in **APPENDIX C**.

### **9.0 FINANCIAL IMPLICATIONS**

9.1 The Council in its March 2012 Budget Report made it clear that access to adult social care services was to be maintained at current levels and to protect frontline services as far as possible. It confirmed that supporting and protecting communities is a key objective. It made it clear that this is "...about making the best possible use of our resources to meet the needs of Sheffield and its people. This means protecting services for people that most need extra help and support from the Council and focusing our investment on efficient services that people and local communities really need".

9.2 In this service area, as part of the overall saving, target reductions are required of £835,000 (after any re-provision costs, loss of income and staff reduction costs) in the financial years 2012-13 and 2013-14.

9.3 By reconfiguring services some investment will be released. Further savings will be made as a result of reduced care home

admissions need to be identified and used to fund increasing demand as the numbers of people with dementia living at home increases.

## **10.0 HUMAN RESOURCE IMPLICATIONS**

10.1 It is recognised there may be changes that may follow on that will provide concerns for staff. In the event of this, staff and Trade Unions will be fully consulted on any specific proposals that may affect them.

## **11.0 LEGAL IMPLICATIONS**

11.1 The Council's powers and duties to provide services for people suffering from dementia primarily flow from Sections 21 and 29 of the National Assistance Act 1948, Section 2 of the Chronically Sick and Disabled Persons Act 1970 and Section 117 of the Mental Health Act 1983.

11.2 In exercising its discretion in this area, the Council needs to be mindful of the Public Sector Equality Duty contained in Section 149 of the Equality Act 2010, that is the duty to have due regard to the need to:-

- (a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Act;
- (b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it; and
- (c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

This includes having due regard to the need to:-

- (a) remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic; and
- (b) take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it.

Disability and age are protected characteristics.

11.3 The attached Equality Impact Assessment addresses the need to ensure that any proposals will not have a disproportionate impact on any one group of people and this should be further considered during the proposed additional consultation exercise. Once this exercise has been completed, the EIA should be updated in relation to any resulting recommendations, and the revised EIA and the outcomes of the consultation should inform subsequent decision making on

these issues.

11.4 The consultation process will be planned appropriately (including consideration of equality issues) with those who will be affected by the proposals, ensuring that they are offered the opportunity to comment and that any issues raised are fully considered. The respective roles of the Council and Sheffield Health and Social Care Trust in the consultation exercise should be clearly established.

11.5 It is understood that the full implications for staff including redeployment and redundancy options will be fully explored as part of this process.

## 12.0 EQUALITY OF OPPORTUNITY

12.1 An Equalities Impact Assessment (EIA) has been completed **(See Appendix C)**

12.2 The groups most affected by dementia are:

- Older people due to the age related nature of the condition
- Women, as more survive to an older age than men.
- BME communities because of the lower early diagnosis rates.
- Carers who often undertake the burden of supporting people with dementia.

12.3 The involvement exercise was designed to follow good practice to ensure it:

- Was accessible and representative.
- Monitored engagement with protected groups throughout the process, and address gaps where required
- Carried out equality monitoring of responses where appropriate.
- Carried out equality analysis of findings/key themes/issues etc, by protected groups where appropriate.

12.4 The consultation to be undertaken by the Sheffield City Council and Sheffield health and Social Care Trust will ensure that as far as possible the views of the groups identified in the EIA are taken into account.

## **13.0 REASONS FOR RECOMMENDATIONS**

- 13.1 The responses to the involvement exercise summarised in this report identified some shortcomings in the existing support arrangements for people with dementia and the need for change. It also highlighted practice changes which will help them to live well at home.
- 12.2 The report recognises the need to ensure adequate investment in services to support people with dementia in the early stages and also for those people with complex needs.
- 12.3 In addition it sets out the requirement to identify savings. It proposes to achieve those savings through exploring the potential to reduce the number of buildings needed to deliver the service whilst maintaining the overall service levels.
- 12.4 It sets out a plan for consultation on these proposals to be undertaken by the Sheffield City Council and Sheffield Health and Social Care Trust.

## **13.0 RECOMMENDATIONS**

- (1) That Cabinet notes the outcome of the Involvement Exercise and in particular thanks the Alzheimer's Society for the production of the report on the views of people with dementia.
- (2) That Cabinet acknowledges in the light of this that support for people with dementia needs to change.
- (3) That Cabinet agrees to consult with people with dementia and their carers to on how services can be changed in the light of these findings and to achieve the required savings and asks the Sheffield Health and Social Care Trust to work with the City Council in this consultation exercise.
- (4) That Cabinet agrees that the consultation exercise referred to in (3) above will include consulting on how alternative, and a wider range of, support and services, and the increased use of personal budgets could be developed to allow the potential closure of Norbury by the end of March 2013 and Bole Hill View by March 2014.
- (5) That the Executive Director, Communities, be given delegated authority:-
  - (a) to finalise arrangements for carrying out the consultation exercise referred to in (3) above, including

making appropriate arrangements with Sheffield Health and Social Care Trust; and

(b) to implement such changes to the provision of services for people with dementia as he shall consider appropriate, such authority to be exercised following the conclusion of the consultation exercise and having due regard to its outcome, and in consultation with the Cabinet Member for Health, Care and Independent Living, and further provided that all associated costs are covered by available budgets.

**APPENDIX A:**



**Sheffield Leading the Way - a dementia friendly city by 2015**



**Tell us what a dementia friendly Sheffield looks and feels like by 2015 in words or pictures:-**

**NO STAMP  
NEEDED**

**Freeport NEA5527  
Quality & Development Team  
Corporate Mail Facility  
Town Hall  
Sheffield  
S1 2ZZ**

**“ I have dementia... but I also have a life ”**

For more information please visit [www.sheffield.gov.uk/dementia](http://www.sheffield.gov.uk/dementia)  
or contact Howard Waddicor, Phone: 0114 205 7130  
Email: [practicedevelop@sheffield.gov.uk](mailto:practicedevelop@sheffield.gov.uk)

CP12194

Alternatively, return to us in person: Main Reception,  
Redvers House, Union Street, Sheffield S1 2JQ

## APPENDIX B: Key Themes Identified

| Level   | Types of support   | People with dementia  | Themes emerging   |
|---|--|---|---|
| <b>1. Promoting lifelong health and wellbeing</b> | <ul style="list-style-type: none"> <li>• Support for everyone.</li> <li>• Building personal and community resilience</li> <li>• Public Information.</li> </ul> | <ul style="list-style-type: none"> <li>• Awareness campaigns</li> <li>• Stroke reduction campaigns</li> </ul> | <ul style="list-style-type: none"> <li>• Dementia Friendly Communities can make a difference but this will be a long term impact – less relevant for people with dementia now</li> <li>• Importance of awareness for all – individuals carers and professionals – especially in primary care</li> <li>• Dementia Alliance would be welcomed – anything that gets people to understand the needs</li> <li>• Early diagnosis crucial – especially important for early onset dementia. Helps people make adjustments and plan for the future. It gives people access to anti-dementia medication</li> <li>• Using ‘well- being’ cafes (similar to Muslim Elder Support Projects) is a way to share healthy lifestyle information and reduce vascular dementia</li> <li>• Organisations like banks often unhelpful to people who forget passwords or where one partner loses capacity to manage finances and will sometimes refuse to deal with carers</li> <li>• “Increasingly organisations, including Sheffield City Council, require people to conduct business online, or in person. This presents barriers to people with dementia and others. There is learning here from some utility companies such as British Gas who have established a vulnerable people team that can respond flexibly and sensitively”</li> </ul> |

| Level   | Types of support   | People with dementia   | Themes emerging  |
|---|--|--|--|
| <b>2. Early, short term, or one off interventions promoting recovery and independence</b> | <b>a) Community based</b><br>Support for people who are close to needing significant support. <ul style="list-style-type: none"> <li>• Investment in third sector and community organisations.</li> <li>• Self Help</li> <li>• Specialist advice and information</li> <li>• Carer support</li> <li>• Befriending</li> <li>• Assistive technology</li> <li>• Lunch clubs</li> </ul> | <ul style="list-style-type: none"> <li>• Dementia Cafes</li> <li>• Dementia Adviser service</li> <li>• Peer support</li> <li>• Link to primary care to support post diagnosis</li> </ul> | <ul style="list-style-type: none"> <li>• Dementia cafes are well regarded. Key features are the peer support and the availability of experienced, thoughtful staff who can help advise informally.</li> <li>• We need a café for the Muslim communities and we will work with you to set one up.</li> <li>• Question about whether there should be cafes solely for people with dementia?</li> <li>• Caring and Coping, Coping with Forgetting are valuable in terms of understanding and managing but also create basis for peer support - Needs to be available for all – waiting lists are too long</li> <li>• Proactive information, advice and support crucial. The Dementia Adviser service could be a basis for local model. To cope with increasing rates of diagnosis there needs greater investment</li> <li>• Blue Badges for people with dementia? – the criteria is not currently not clear but people with dementia are not excluded</li> <li>• Carer's need information about what is available. The type of information they require varies depending on their own circumstances and level of need</li> <li>• The needs of the carer and the person with dementia are not always the same but the carer needs to be sure that the person with dementia is safe and is getting the right support.</li> <li>• Flexible, personalised services that respect individual difference are fundamental. There is no one solution</li> <li>• Dignity and respect should be at the heart of all interventions</li> <li>• Admiral Nurses – a helpline available online and via telephone. There is a debate to be had about whether Sheffield would benefit from the service</li> </ul> |



| Level | Types of support   | People with dementia | Themes emerging  |
|-------|--|----------------------|--|
|       |  |                      | <ul style="list-style-type: none"> <li>• ‘Singing for the Brain’ and ‘Lost Chord’ work well for people who find other forms of communicating difficult</li> <li>• Carer breaks fund help carers decide what support they need</li> <li>• Accurate and early information about contributions to the cost of services help people make decisions</li> <li>• The ‘Help Yourself Directory’ is a good source of information for people at all stages</li> </ul>  |
|       | <p><b>b) Acute or specialist</b></p> <ul style="list-style-type: none"> <li>• Short term or intensive support.</li> <li>• Reablement. Equipment and adaptations</li> </ul> |                      | <ul style="list-style-type: none"> <li>• Long delays were reported in the social care assessment process</li> <li>• Some expressed concern that self-directed support may exclude people with dementia. Some carers reported that it was could be onerous at a time when support should be timely. Others welcomed the opportunity but found it more problematic as an individuals capacity to choose diminished.</li> <li>• There is a concern that support planners lack specialist knowledge</li> <li>• Joined up working health and social care is – access to Rapid Response Team and CPNs</li> <li>• Responses to crises need to be better co-ordinated and if need be truly rapid if admissions to care are to be avoided</li> <li>• Avoid too many people being involved – co-ordinate care better</li> <li>• Crises can be avoided by effective contingency planning</li> <li>• Home support, even specialist services, seem to lack the skills and understanding of how to support people with dementia. Particular concern was raised about those people who live alone.</li> </ul> |

| Level   | Types of support   | People with dementia         | Themes emerging  |
|---|--|------------------------------|--|
| <b>3. Medium to long term care and support focused on stability and quality of life</b> | <b>a) Community based</b> <ul style="list-style-type: none"> <li>• Personal Budgets.</li> <li>• Medium to long-term assistance to continue living at home.</li> <li>• Home support</li> <li>• Day opportunities</li> </ul> |                              | <ul style="list-style-type: none"> <li>• Resource centre model works well for people with most complex needs, though not everybody wants this.</li> <li>• People value the skills offered by resource centres – they say that for some people the private sector cannot offer the same level of care</li> <li>• Can the private sector be trusted to deliver the quality of support?</li> <li>• People need good care not just en-suite facilities</li> <li>• Consistent care – familiar faces make a difference to the wellbeing of people with dementia</li> <li>• Not all support should be in day centres or respite care – some people do not want that or say that the experience only adds to their confusion and distress</li> <li>• “My dad would hate to go to a day centre but my mum needs a break”</li> </ul> |
|   | <b>b) Acute (or away from home)</b> <ul style="list-style-type: none"> <li>• Medium to long-term 24 hour assistance to live safely.</li> <li>• Residential and nursing care.</li> </ul>                                    | Residential and Nursing care | Concern about the skill levels in some care homes  |

## APPENDIX C: Equality Impact Assessment



**Name of policy/project/decision:**  
**Transforming Services for People with Dementia Living at Home**

**Status of policy/project/decision:** New

**Name of person(s) writing EIA:** Howard Waddicor

**Date:** 14/5/12

**Updated :** 17/9/12                      **Service:** Adult Social Care Commissioning

**Portfolio:** Communities

**What are the brief aims of the policy/project/decision?** To improve the quality and range of services to support people with dementia at home

**Are there any potential Council staffing implications, include workforce diversity?** Yes

| Areas of possible impact    | Impact   | Impact level | Explanation and evidence  |
|-----------------------------|----------|--------------|---|
| <b>Age</b>                  | Positive | High         | Dementia is an age related condition. The Sheffield Health Needs assessment shows a projected increase in late onset dementia in Sheffield from 6,137 in 2010 to 8,292 in 2025, an increase of over 35%. The greatest increase in prevalence of dementia in Sheffield is predicted to occur for those people aged 80 and over. The changes are anticipated to allow people to remain at home as long as possible with the right type of support |
| <b>Disability</b>           | Positive | High         | Critical to a positive outcome for this and all groups affected is an integrated, whole-system approach to transforming services. This requires dedicated resources to manage the project throughout the stages.  |
| <b>Pregnancy /maternity</b> | Neutral  |              | No disproportionate impact anticipated  |
| <b>Race</b>                 | Positive | Medium       | There is evidence from a report compiled by the NHSS Community Development BME Mental Health Team that some BME communities are unable to gain early diagnosis and support because of shortcomings in the way symptoms are understood   |

| Areas of possible impact  | Impact   | Impact level | Explanation and evidence   |
|---------------------------|----------|--------------|--|
|                           |          |              | <p>and a reluctance to attend GP services. Following diagnosis the existing support arrangements are not always flexible or culturally appropriate. Though the number of BME elders is currently low the numbers are due to increase. The numbers of Pakistani elders 65+ will increase by 250 by 2025. The proposed changes may reduce investment in traditional services and increase opportunities for funding for people from BME communities to access social care support in a more personalised flexible way</p> <p>The revised information and advice service will be expected to work with existing BME organisations to ensure that there is a wider understanding of the need for early diagnosis and support for people with dementia.</p> |
| <b>Religion/belief</b>    | Positive | Low          | <p>Recent prevention work with the Muslim Elders Support project has identified the potential of using faith based sessions to broaden understanding of the impact of poor lifestyles on the level of vascular dementia in communities. A preventative approach has the potential to reduce this in the long term by reducing the number of strokes</p>  |
| <b>Sex</b>                | Positive | Medium       | <p>There are more older women than men so there are proportionately more women with dementia. In addition the Sheffield Carers Strategy shows that most caring is done by women. Improvements in support to carers, as proposed in these changes, will reduce the burden of caring for people with dementia</p>  |
| <b>Sexual orientation</b> | Positive | Medium       | <p>Dementia has the potential to have a profound impact on the lives of the individual and those who care for them. The purpose of the change is to help reduce the impact of the</p>  |

| <b>Areas of possible impact</b>   | <b>Impact</b> | <b>Impact level</b> | <b>Explanation and evidence</b>  |
|---|---------------|---------------------|--|
|   |               |                     | condition by providing personalised support in a way that allows people to live a normal life for as long as possible.   |
| <b>Transgender</b>  | Positive      |                     | No disproportionate impact anticipated   |
| <b>Financial inclusion, poverty, social justice, cohesion or carers</b> | Positive      |                     | The National Dementia Strategy 2009 and the Sheffield Carer Breaks Strategy for People with Dementia 2006 both highlighted the significant impact on carers of looking after someone with dementia. The involvement exercise will give carers the opportunity to shape the way support is offered to people with dementia. |
| <b>Voluntary, community &amp; faith sector</b>                          | Neutral       |                     | No disproportionate impact anticipated   |
| <b>Other/additional: Existing service users</b>                         | Negative      | High                | Those people with dementia are amongst the most vulnerable people living at home. By the nature of the condition change can be difficult for some users. Any transitions need to be carefully managed to reduce the impact   |

## Action plan

| Area of impact | Action and mitigation   | Lead, timescale and how it will be monitored/reviewed                                   | Update October 2012  |
|----------------|---|---|--|
| All groups     | <ul style="list-style-type: none"> <li>- Follow good practice to ensure the exercise is accessible and representative.</li> <li>- Monitor engagement with protected groups throughout the process, and address gaps where required</li> <li>- Carry out equality monitoring of responses where appropriate.</li> <li>- Carry out equality analysis of findings/key themes/issues etc, by protected groups where appropriate.</li> </ul> | Howard Waddicor - Planned Cabinet report for May 2012<br>Involvement June - August 2012 | <p>A range of ways to engage with people has been used to make the exercise accessible and representative.</p> <ul style="list-style-type: none"> <li>• A small reference group was established for the life of the exercise.</li> <li>• A 'talk to us about living well' flier campaign <a href="http://www.sheffield.gov.uk/talktous">www.sheffield.gov.uk/talktous</a> featuring and linked to the exercise was sent to 109 GP surgeries, posted to around 8,600 adult social care existing customers, sent via an email network including 260 individuals and organisations: (Age - 19, Carers - 7, Disability - 8, Faith sector - 5, Financial inclusion social justice - 3, Race - 7, Transgender - 1, Voluntary community and faith sector - 31). The campaign also featured in information on SCC website news, SCC internal intranet</li> </ul> |

| Area of impact | Action and mitigation | Lead, timescale and how it will be monitored/reviewed | Update October 2012  |
|----------------|-----------------------|---|--|
|                |                       |   | <p>and via Twitter.</p> <ul style="list-style-type: none"> <li>• A specific exercise to gather the views of people who have dementia (delivered by the Alzheimer's Society).</li> <li>• A dedicated telephone number and email address featured in communications.</li> <li>• A dedicated event using a range of interactive exercises for carers of people who have dementia to respond to 5 core questions, attended by 60 people, either carers, or from a broad range of representative groups, e.g. 50+, ROSHNI, LINK &amp; NHS. Carers of people who use the existing resource centres were invited to attend (a BSL interpreter was present at this meeting to provide support if necessary).</li> <li>• A meeting with the Muslim Dementia Group at the Yemeni Community Centre</li> <li>• via a letter from the Executive Director, Communities to 260</li> </ul> |

| Area of impact | Action and mitigation | Lead, timescale and how it will be monitored/reviewed | Update October 2012  |
|----------------|-----------------------|---|--|
|                |                       |   | <p>stakeholders seeking feedback.</p> <ul style="list-style-type: none"> <li>• via a pop-up shop in the city centre in week commencing 20/8/12 respondees were asked to comment of 5 core questions, or complete a postcard.</li> <li>• via a dedicated webpage <a href="http://www.sheffield.gov.uk/dementia">www.sheffield.gov.uk/dementia</a></li> <li>• via visits to specific groups e.g. Darnall Dementia , Age UK, Sheffield Alzheimer's Society,</li> <li>• Via a widely circulated freepost return postcard asking respondees to 'tell us in words &amp; pictures what a dementia friendly Sheffield looks &amp; feels like', which was commissioned as part of the exercise and agreed via the reference group.</li> <li>• A meeting with the BME Dementia group to explore opportunities for earlier diagnosis</li> <li>• The postcard was distributed to around 7,000 older people who are existing social care customers. <ul style="list-style-type: none"> <li>○ via x GP surgeries.</li> </ul> </li> </ul> |



| Area of impact | Action and mitigation   | Lead, timescale and how it will be monitored/reviewed | Update October 2012   |
|----------------|---|---|---|
|                |   |   | <ul style="list-style-type: none"> <li>○ via a pop-up shop (150).</li> <li>○ via the dedicated webpage where an electronic version of the card could be completed.</li> </ul> <p>Responses received to date (24/8/12)</p> <ul style="list-style-type: none"> <li>• Responses received at Carers event</li> <li>• Responses received at pop-up shop</li> <li>• 16 email and telephone from stakeholders</li> <li>• 61 returned postcards</li> <li>• visited carers</li> <li>• Addressing gaps Approach made to Deaf Club re visit to cover 'talk to us' issues, to be arranged.</li> </ul> <p>It has not been possible to directly understand the needs of gay and lesbians who have dementia. Further work is being considered to identify what steps will be most effective.</p> |
| All groups     | We will involve people with dementia and, separately, their carers through the Community Dementia Forum hosted by the Alzheimer's | Howard Waddicor - June to August 2012                 | - Sheffield Alzheimer's Society have undertaken an involvement exercise specifically with people with dementia.   |

| Area of impact | Action and mitigation   | Lead, timescale and how it will be monitored/reviewed | Update October 2012   |
|----------------|---|---|---|
|                | Society and other groups.   |   | - A carers event was held on 31/7/12 – over 50 carers have attended   |
| All groups     | All stakeholders will be involved appropriately in developing the model. This will include GPs as part of the 'Right First Time Project'                | Howard Waddicor by August 2012                        | All stakeholders invited to contribute by letter from Richard Webb in July 2012.  |
| All groups     | The strategic approach will be shared at the Dementia Programme Board chaired by Richard Webb   | Richard Webb by August 2012                           | <ul style="list-style-type: none"> <li>- The proposals for involvement were shared at the July 2012 Dementia Programme Board.</li> <li>- An initial report will be presented to the shadow Health and Wellbeing Board on 31/8/12</li> <li>- Further report planned for Scrutiny on 12/9/12</li> </ul> |
| All groups     | Proposals for change will include a risk management plan for existing users and carers to ensure that any changes have the minimum impact on this group | Howard Waddicor -                                     | As part of the proposals to reduce the number of buildings required to support people a consultation process will work with users and carers to consider how the impact of changing venues can be minimised.  |

**APPENDIX D: Extract from Report compiled by Sheffield Alzheimer's Society. The full report can be viewed at:**  
**<https://www.sheffield.gov.uk/caresupport/policy/dementia-support.html>**

## **Shaping the Future of Dementia Care: views from people with dementia**

### **How can Sheffield communities better understand the needs of people with dementia so that living at home is a safe and positive option?**

Throughout this survey, people with dementia have said how important still being part of their communities is to them. However, this does not always refer to their local geographical community because many people were talking about the 'dementia community' where people have told us they feel understood, safe and able to get a great deal of informal support.

There appears to be a tendency for people/couples to become more isolated with this illness because it becomes harder to get to places, particularly if the person with dementia lives on their own. The person with dementia can also start to feel less confident and relaxed in company, as their recognition of people becomes difficult and they may struggle more with conversation. For these reasons, many people with dementia on their own and couples find it more relaxing and easier to move their social circle within a network of cafes, groups and events where they will be with people in similar situations. Within this study, many of the responses from people with dementia voiced this trend.

The benefits of a dementia community may arise from discomfort in more general communities and this discomfort could be related to issues of exclusion and poor awareness. However, in the short term and possibly in addition to any increased 'dementia friendliness' of local communities, people with dementia and their families are queuing up (literally) for this type of support as validated by the waiting list for every peer support activity available through the Alzheimer's Society.

### **Recommendation**

- This type of 'in the same boat' social support is highly valued and needs to increase greatly and as quickly as possible so that it is more available within all local geographical communities. It is important to recognise the specialised nature of this type of support. People with dementia want support from people who know about, understand and can help facilitate their involvement in wider social and support networks and this is particularly true for the many people who live on their own.

### **What is good support for people living with dementia at home?**

Although there were greatly differing views from people with dementia about the types of support they would like, ranging from the extremely adventurous to those that rejected the idea of any support for themselves, the one thing

everyone agreed on was that groups, activities and services that were geared to both themselves and their partner/supporters provided the most acceptable type of support for the person with dementia.

An interesting artefact of this survey is that in the context of these interviews, many people talked about and considered services that they are likely to have rejected when raised within the context of an assessment for support. Many people expressed surprise, pleasure and approval at being asked their views in this study and it is a strong possibility that an increased sense of self esteem and confidence (due to being 'consulted') made it less threatening to consider support options. Assessment processes (the gateway to services) do tend to focus on problems, and can feel invasive and humiliating for the person with dementia. Assessment processes are often a deterrent to seeking services because it is known that the person with dementia will find them stressful.

Assessment processes need to be respectful in order that the person doing them can also be so. It is not possible for assessors to be 'respectful' of the person with dementia if the tools they are using provide a stressful and demeaning experience for the person with dementia.

In this day and age of single assessment processes, it is of significant concern to see so many people still doing their own assessments, so many different people involved in assessments and the repeating of questions and the confirming of people's problems over and over again.

In considering support options in this survey most people with dementia did not make a distinction between social contact and support, with only 2 people in this survey making the connection that support options were services that they would pay for.

Having choice and control has been very clearly confirmed in this survey as vitally important to people with dementia. On the whole, this will mean that the person with dementia needs to have involvement in services/groups and activities earlier than is currently the case, so that contact is not triggered by carer need but by the wish of the person with dementia or a couple where one person has dementia, to extend their social and support network.

For people in this survey, day care and companion/carer type services have to be more than providing a break for their partner/supporter. They need to be an attractive option. For this to work for people with dementia, choice and control have to precede assessment. The current system, because it tends to be triggered by carer need, immediately enters an assessment phase, at which point the person with dementia may have not have any concept of what options they may have.

From the views that people with dementia expressed in this survey, they want to be able to visit, sample, do ½ days, and take partners/supporters before making a choice. They also need to feel that they can choose not to do

something. It follows that there is then a definite purpose to the assessment which the person with dementia can understand and co-operate with.

People with dementia can end up refusing all services because they are feeling out of control and suspicious that they are entering a slippery slope ending in a care home. This was explicitly said by one person in the survey as a reason why she would not go to a day centre.

People spoke movingly about their fear of having to go into a care home, with several people becoming tearful in the interviews either talking about losing their partners, having to go into care or seeing a parent go into a care home. Within this survey, care homes were still a dreaded ending for most people with one person stating that more money should be spent on providing support for families and less on care homes. There was only one person out of the 29 who spoke about entering a care home as a planned and positive option for the future.

### **Recommendations:**

- Assessment processes for formal paid services should build on work already established in the voluntary/charity/informal sector. More formal links should be established between paid-for services and informal support so that the transitions are less obvious and stressful to the person with dementia.
- Assessment processes need to be streamlined and sensitive to the particular fears and concerns people with dementia have to the disturbance to their sense of normality, self worth and autonomy. This would indicate that assessors need to have training in dementia awareness and person centred approaches.
- The number of assessments done by different organisations needs addressing.
- Assessment is better done by a trusted person.
- Services need to provide much greater flexibility around providing relationship/family type support, where the person with dementia is seen as part of a network of reciprocal relationships not just as a single entity with 'needs and problems'.
- Any recent improvements of the care home model do not seem to have altered people's views about them. This does need addressing; it is appalling that so many people's lives are overshadowed by the fear and stress of entering a care home.

### **What is good support for the carers of people with dementia?**

- A strong message from this survey is that good and acceptable support for the person with dementia would give very valuable support to the people who support them.
- Assessments and services that see supporting couples and families as an integral part of supporting the person with dementia.

### **How can we protect existing users of services during any change?**

Several people commented about their fear and dislike of change.

- The commissioning and contracting of services should not interrupt successful services as perceived by the person with dementia. The considerations of continuity and familiarity should be paramount in any development or reconfiguration of services for people with dementia.

### **How can health and social care providers work closer together for the benefit of people with dementia?**

There was a clear message from people with dementia that they do not distinguish between all the different people providing services, except GPs and hospitals.

Four people discussed their GP's and only one of these four was happy with the service provided. The problems mentioned by the other three were, not seeing the same person, waiting times, and a lack of personal interest in themselves, as demonstrated by one person who described the GP as looking at the computer for the whole of her recent consultation.

This is worrying since the role of GP's in relation to people with dementia is likely to be extending in the future because Memory clinics are going to be discharging people back to the care of their GP rather than seeing them in clinic.

Over and over again in this study, people with dementia could not say and did not care particularly about who was organising a service, group, course or activity and this does naturally lead to thinking that we need a great deal more 'one shop stop' approaches where people can access what they want without the multiple assessments and assessors that can be generated by a marketplace model.

Competition between organisations that are increasingly seeking profit to provide services has the potential to lead to greater fragmentation of the 'dementia pathway', a term that was conceived to work on smoothing the difficult and stressful transitions in many people's dementia journey, caused by multiple agencies, lack of joint working and service gaps.

## **Recommendations**

- All health and social care providers need to do much more consultation with people with dementia and make a genuine effort to integrate their perspectives into the commissioning, design and delivery of services intended to support them.
- It is important to work at reducing the effect of 'marketplace' behaviour to avoid any potential stress that this may add to an individual's dementia journey,

Alzheimer's Society, Sheffield  
12 September 2012

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