



Adult Social Care Select Committee

Living Well With Dementia Task Group Report

Purpose of the report: Policy Development and Review

The purpose of the report is comment on Surrey County Council's policy for caring for people Living With Dementia and to ensure that any proposals meet the criteria of the National Dementia Strategy.

Introduction

- 1 In October 2010, the Adult Social Care Select Committee (then know as the Adult and Community Select Committee) set up the 'Living With Dementia Task Group'. The objective of the group was to ensure that Surrey County Council (SCC) developed an appropriate policy to support people in Surrey living with or caring for people with Dementia.
- 2 The group reviewed appropriate literature, met with a number of witnesses and undertook a site visit to produce 17 recommendations, which are listed at the end of this report.

Context

- 3 It is estimated that in the UK 700,000 people have dementia. In Surrey just under 14,000 older people were estimated to have dementia in 2009 – this equates to around 1 in 12 older people (over 65). As the population of older people in Surrey is rising, the number of people with dementia is also expected to increase. Young onset dementia affects approximately 15,000 younger people (aged 30 – 64) in the UK.
- 4 The National Dementia Strategy was published in 2009 by the Department of Health (DoH), and was designed to drive forward improvements for dementia sufferers and their carers across the following key areas –
 - **Improving awareness** – increased public and professional awareness of dementia and an informed and effective workforce for people working with dementia.

- **Early diagnosis and intervention** – good quality early diagnosis, and intervention for all, good quality information for those with dementia and their carers and that enables continuity of support and advice.
 - **Living well with dementia** – by improving the quality of care for people with dementia in home care; respite care/short breaks; intermediate care; general hospitals; care homes.
- 5 In 2009, Surrey County Council's Adult Social Care (ASC) Directorate strategy 2010/11 to 2013/14 embraced four government priorities one of which was 'Living with Dementia'. As a result ASC have been working with NHS Surrey to propose a new strategy of care – 'Dementia and Mental Health Services for Older People in Surrey: Commissioning Strategy 2010 – 2015'. This document is going out to consultation on the 7 July.

Methodology

- 6 The group met up 10 times over a period of 8 months. The time frame of the group was slightly longer than expected due to illness and wanting to ensure that the report was able to comment on the final version of the Surrey strategy.

Review of relevant material and literature

- 7 The group reviewed a number of key pieces of literature to enable them to comment upon current dementia strategy - including:
- Living With Dementia: A National Strategy – Department of Health (2009)
 - Dementia and Mental Health Services for Older People in Surrey: Commissioning Strategy 2010 – 2015 - NHS Surrey and Surrey County Council (2010)
 - The clinical and health economic case for early diagnosis and intervention services in dementia – Department of Health (2009)
 - Counting the Cost – caring for people with dementia on hospital wards – Alzheimer's Society (2010)
 - County Accommodation Strategy for Vulnerable People – Surrey County Council
- 8 The group also held a number of 'witness sessions' with relevant stakeholders including representatives from:
- Surrey Primary Care Trust (PCT)
 - Surrey County Council Senior Management
 - Care staff from both the PCT and SCC
 - Surrey and Borders Mental Health Trust
 - The Alzheimer's Society
 - Action for Carers

- 9 The group also visited the Aztec Centre in Croydon to learn more about their telecare services. Unfortunately, two other site visits to Brighton City Council and Hampshire County Council were cancelled due to adverse weather conditions in January.

CONCLUSIONS

- 10 Overall the group feels that the 'Dementia and Mental Health Services for Older People in Surrey: Commissioning Strategy 2010 – 2015' provides a good platform for implementing the National Dementia Strategy (NDS) in Surrey. Below are particular areas that the group wishes to draw attention to, with the NDS objective which they refer to include underneath each heading in italics.

Public Awareness

(Objective 1: Improving public and professional awareness and understanding of dementia.)

- 11 The group is pleased to see that the Older People's Mental Health (OPMH) strategy proposes to hold a public awareness campaign, to help prevention and early diagnosis of dementia. Members of the group were not previously aware of the 'What's good for your heart, is good for your head' message and feels that this should be disseminated more widely in Surrey. With a reducing financial envelope, the group also feels that ASC should explore how they can work with other council services to promote the public awareness campaign. For example, Croydon Council have set up a mobile memory service known as a POP bus and it may be worthwhile exploring using one of Surrey's six mobile libraries in a similar way. District and Borough services should also be included in the public awareness campaign where possible.

Geographical Cohesiveness

- 12 The group are concerned about the disparity of dementia care across Surrey. Witness sessions told us that there are very different working arrangements across the county resulting in differing standards of performance. Whilst the task group does not wish to impede local flexibility, we believe that more consistency of care is required to all Surrey residents. It is therefore recommended that a standard of care be established and made easily available, so that anyone in Surrey can be aware of what he or she is entitled to when diagnosed with dementia.

GP awareness and detection

(Objective 2: Good-quality early diagnosis and intervention for all)

- 13 Early diagnosis has been recognised in a large amount of literature as key to allowing people with dementia to live at home for longer. However, the task group are concerned about whether all GPs currently have the time and confidence to make a dementia diagnosis. In their 2010 manifesto, The Royal College of General Practitioners (RCGP) recommended that:

1. GPs to have more time with their patients

The ageing population means that more patients will have long-term and increasingly complex conditions. They will need more time with their GP to discuss their care and treatment options. We call for the average consultation time between a patient and his or her GP to be increased.

The group understands that this is a wider problem and not one that can be dealt with in this report or by the Council alone. However, it would like to propose that the Health Scrutiny Committee looks at this area in-depth in a future meeting, with a view to possibly lobbying the Government on the issue.

- 14 The OPMH strategy recommends that a Primary Care best practice unit be set up for the first three years of the strategy. The group strongly supports this recommendation and feels that the best practice unit should be evaluated after three years with the possibility that it may continue to be in place for the whole life of the strategy, to allow continuous professional development opportunities for GPs in handling dementia.

Care Pathway

(Objective 3: Good quality information for those diagnosed with dementia and their carers)

- 15 The five-tier model as produced in the OPMH strategy provides a useful way of understanding what living with dementia may look like in Surrey. Although the task group understands that there is not one generic experience for a person living with dementia, they feel that this model could be simplified to produce a one or two page 'care pathway', which identifies the various different services and assistance available. It is felt that this could provide assurance and comfort to those people who have been diagnosed with dementia and their carers.

Dementia Navigators

(Objective 4: Enabling easy access to care, support and advice following diagnosis)

- 16 The group strongly supports the role of dementia navigators, as suggested in the National Dementia Strategy (where they are referred to as dementia advisors). As the NDS suggests, the role of a dementia navigator would not be that of intensive case management, instead they would provide a single identifiable point of contact with knowledge of and direct access to the whole range of services. The group believes that dementia navigators are key to early intervention and significant investment in this area could prevent the need for costly intervention at a later stage. Members would like a commitment from the Council to invest in the dementia navigator role in the first year of the strategy.

Carers

(Objective 7: Implementing the Carers' Strategy)

- 17 If Surrey is to move towards people living with dementia to stay in their homes for longer, then it is essential that we provide full support and training to the carers that are enabling them to do this. Surrey's carers are an asset to the county – this has been acknowledged by Officers from ASC and all of the partner organisations that the group have spoken too.
- 18 The group feels that carers assessments could prove a useful tool to ascertain that carers are being supported and have the opportunities, breaks and training necessary to care for a person living with dementia. We are however concerned that the Council only carried out 13.2% of services users assessments in 2009/10 – which placed SCC in the bottom quartile of local authorities. Although not every person using social care has a carer, and therefore the Council will never be able to achieve 100% on this performance indicator, the group feels that the number of carers' assessments should be higher. It is therefore suggested that a review is carried out to determine how to increase the numbers of carers assessments, and whether any changes are necessary in order to make the assessment more useful - both to the carer and the Council.
- 19 If people with dementia are to be enabled to stay in their homes for longer, carers need to be provided with the training to cope with their increasing needs. Carer training is not explicitly referred to in the current OPMH strategy. It is therefore recommended that a carer training scheme be established, whether it consists of training provided in-house, or by signposting and supporting people to attend training courses provided by a voluntary organisation. Carer training needs should also be included as part of the carers assessment.

Telecare

(Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carer)

- 20 The group believes that telecare is a fundamental preventative tool and key to allowing people living with dementia to stay in their own homes for longer. They were pleased to see the investment from the Leader in Dementia Telecare through his Policy Initiatives Fund. The task group is confident that this funding will prove to be a successful 'invest to save' scheme and therefore asks the Leader to consider a similar investment next year.
- 21 The group were concerned to hear that the previous telecare schemes that had been in place in Surrey had been underspent – it is clear that the use of telecare in Surrey is underdeveloped compared to many other local authorities. There is a key need to improve the marketing and promotion of telecare, and to reduce the stigma that is sometimes attached to the technology. The group would therefore recommend the proposal that a short free trial is offered to prospective users of telecare before deciding whether they would like to buy it, either through their personal budget, if they are eligible for Adult Social Care services, or to

be paid by themselves. This may help persuade people who are sceptical about using the equipment.

- 22 The task group heard from witnesses that telecare schemes are sometimes implemented too late, in that the older person was unable to learn how to use the equipment and it was therefore ineffective. The group therefore asks that the telecare strategy ensures that telecare packages are implemented in a timely way. Dementia navigators could have a role in referring people living with dementia to telecare schemes that could help them.
- 23 The group are interested to investigate whether a 24 hour emergency call out service could be developed for people concerned about elderly family members, friends or neighbours. With the telecare strategy in development, it may be worth considering such a service, perhaps supported by the same contact centres that deal with telecare responses in the District and Boroughs.

In-reach teams

(Objective 8: Improved quality of care for people with dementia in general hospitals.

- 24 The Alzheimer's Society 'Counting the Cost' report calculated that people with dementia over 65 years of age are currently occupying up to a quarter of NHS beds at any one time, and generally spend a longer time in hospital than other people going in for the same procedure. We are therefore pleased to see that the OPMH strategy recommends the following action:

'Ensure there is a clinician in acute general hospitals that will lead on improving quality of care for older people with mental health problems'

The group would like to strongly endorse this and reiterate that investment into this role and the hospital liaison service would release funding from caring for people with dementia from expensive acute settings to be re-invested into alternative settings within the community.

Young Onset Dementia

- 25 Dementia under the age of 65 is relatively rare, but can cause deep distress for individuals and their families and often require additional services in addition to older people who have dementia. The group is aware that Surrey has developed a draft Young Onset Dementia Strategy 2009 – 2014, and would request that this strategy is finalised and implemented alongside the OPMH strategy.

Member Awareness

(Objective 1: Improving public and professional awareness and understanding of dementia)

- 26 The Members of the task group have learnt a great deal about living with dementia and will continue to act as informal 'champions' for dementia

through their work on the ASC select committee. We would like to see all Members become more aware of the issues around caring for people living with dementia. It is suggested that all Members are invited to the dementia summit to take place in July and are kept updated with the progress of the implementation of the OPMH strategy. ASC should be aware that each Member has an allocation, and some Members may be willing to use part of this allocation to help local schemes, such as dementia cafes.

Joint-working/Resources

(Objective 14: A joint commissioning strategy for dementia)

- 27 Dementia is a chronic, long-term condition – it requires a variety of care and treatment that cannot be dealt with by one organisation alone. The group is extremely pleased to see that the OPMH strategy is a **joint** strategy between NHS Surrey and SCC, and it is imperative that this joint working continues in order to ensure successful implementation. Both organisations will have to ensure that enough resources are in place to ensure that the strategy is implemented successfully. With this in mind, Members would like to be provided with named contacts for Officers with responsibility for the delivery of the OPMH strategy in both the SCC and NHS Surrey and details of the staffing arrangements that will support them to do this.

Performance Monitoring

- 28 The OPMH strategy aims to set high standards of dementia care and careful performance monitoring will be required to see that that this challenging piece of work is completed. The task group would therefore like to meet quarterly for the first year of the strategy to review progress in this important piece of work.

Conclusions

Financial and value for money implications

- 29 The Members are concerned that there is not a comprehensive indication of the funding that is available for the services proposed in the OPMH strategy. The current national spend on Dementia is approximately £17 billion per year and this is estimated to rise to over £50 billion year within 30 years. Thus, the successful implementation of the strategy is imperative to ensure that costs can be managed over the coming years. It is therefore of the utmost importance that the Council and NHS Surrey work together to commit resources to the strategy, and continue to review investment throughout the lifespan of the project.

Equalities Implications

- 30 Improving care for people living with dementia will benefit many vulnerable groups such as the elderly and carers. The implementation of the Young Onset Dementia Strategy will benefit people with learning

difficulties – the prevalence of young onset dementia is particularly high amongst those with downs syndrome.

Risk Management Implications

- 31 The successful implementation of the strategy will require significant partnership working and buy in from stakeholders and therefore a full consultation with these groups will be required to secure support for the strategy at an early stage.

Implications for the Council's Priorities or Community Strategy/Local Area Agreement Targets

- 32 Living with Dementia is one of the four priorities of the Adult Social Care Service. The implementation of the OPMH strategy will contribute towards the following Local Area Agreement targets:
- a. NI 125 Achieving independence for Older People through rehabilitation/intermediate care
 - b. NI 135 Carers receiving needs assessment or review and a specific carers service or advice and information.

Recommendations:

- (a) *That Adult Social Care (ASC) explores how other Council services can assist them in promoting a public awareness campaign (for example, the use of a mobile library) as well as District and Borough Councils.*
- (b) *That a standard of care is established so that all Surrey residents can be aware of what services they are entitled to when diagnosed with dementia.*
- (c) *That the Health Scrutiny Committee considers GP consultation times at a future meeting, and whether there is a case for the Cabinet to lobby the government for their extension.*
- (d) *That Members are provided with more information regarding the GP best practice unit, in particular whether any investment is planned for this initiative.*
- (e) *That a simple, one sheet 'care pathway' is established to let patients know what type of care and services they may experience when diagnosed with dementia.*
- (f) *That a significant investment is made for the provision of Dementia Navigators.*
- (g) *That a review is carried out to determine how to increase the low numbers of Carers Assessments in Surrey.*
- (h) *That a Carer training scheme is established.*

- (i) *That continued investment for telecare is considered for an 'invest to save' bid.*
 - (j) *That telecare is introduced at an early stage when a service user is comfortable using the technology.*
 - (k) *That short free telecare trials are provided for people with dementia, to reduce the stigma of the equipment.*
 - (l) *That the provision of a 24-hour emergency callout service is established.*
 - (m) *That the draft Surrey Young Onset Dementia Strategy is finalised as implement alongside the Older People Mental Health Strategy (OMPH) strategy.*
 - (n) *That all Members are invited to the dementia summit on 7 July 2010 and that the Members of the task group continue to act as informal 'champions' for dementia – raising awareness amongst other Councillors and residents.*
 - (o) *That the service considers approaching Members to use part of their Member allocations to help fund local dementia projects in their area.*
 - (p) *That a named officer with responsibility for dementia is determined in both SCC and the PCT, and that Members are given details of the staffing arrangements that are in place to deliver the OMPHS.*
 - (q) *That the task group continues to meet for one year on a quarterly basis, in a performance-monitoring role.*
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Sources/background papers:

Counting the Cost – caring for people with dementia on hospital wards – Alzheimer's Society (2010)
County Accommodation Strategy for Vulnerable People – Surrey County Council
Dementia and Mental Health Services for Older People in Surrey: Commissioning Strategy 2010 – 2015 - NHS Surrey and Surrey County Council (2010)
Leading the Way – High Quality Care for All through General Practice – The Royal College of General Practitioners
Living With Dementia: A National Strategy – Department of Health (2009)
Surrey Young Onset Dementia Strategy – Surrey Primary Care Trust and Surrey County Council

ITEM 11

The Aztec Project – Providing Assistive Technology for People with Dementia and their Carers in Croydon

The clinical and health economic case for early diagnosis and intervention services in dementia – Department of Health (2009)

www.alzheimers.org.uk