



House of Commons
All-Party Parliamentary Group
on Dementia

The £20 billion question

An inquiry into improving lives
through cost-effective
dementia services

July 2011

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Foreword

Dementia is a colossal challenge that costs our economy billions of pounds every year. But even with the huge sums of money spent, we know a lot is wasted on poor-quality care and many people with dementia continue to be let down by the current system.

Poor-quality care means people with dementia and their families often go without proper support until they reach crisis point, and this brings with it a huge physical and emotional burden for them. Furthermore, the intensive type of care needed when people reach this point costs the state a huge amount every year, much of which is unnecessary and completely avoidable.

In the current financial climate, when we already see cuts to services in our communities, and with the knowledge that 100,000 people develop dementia every year, we have now reached a point when we can no longer ignore the issue. We have to ensure money in this area is spent more effectively in supporting people with dementia and their families properly and in a timely way. If we do not do so, we will find ourselves in a situation of unqualified crisis.

For this reason the All-Party Parliamentary Group (APPG) on Dementia decided to lead this inquiry. A range of experts have now contributed their ideas on how we can make better use of the resources spent on dementia while at the same time improving outcomes for people. We hope the evidence and case studies highlighted will be shared across the UK, empowering the NHS, local authorities and others to deliver the best care at the right price.

We urgently need people across health and social care to regard work in this area as a priority, and understand that providing good-quality care for people with dementia can help deliver against wider goals for the system. By gathering more practical examples and making them accessible to the people who design and provide services, together we can start to tackle the challenge ahead, both by meeting the demands of the difficult financial climate and transforming the way care is delivered.



Baroness Greenross
Chair of the All-Party Parliamentary Group on Dementia
July 2011

All-Party Parliamentary Group on Dementia

The All-Party Parliamentary Group (APPG) on Dementia was created in 2007 to build support for dementia to become a publicly stated health and social care priority, and therefore meet one of the greatest challenges presented by our ageing population.

The terms of reference of the inquiry

In December 2010 the APPG on Dementia announced that it would undertake an inquiry into how to make the best use of the resources currently spent on dementia while at the same time improving outcomes for people with dementia and carers.

A key stimulus for this inquiry was the current difficult financial climate for public services, and also the existing evidence to show that although dementia costs the UK £20 billion a year, much of this money is spent inefficiently on poor-quality care.

The APPG was interested to find current examples of good practice in dementia care, which are both value for money and consistently deliver good outcomes for people. It also wanted to bring these together in a report as a useful tool that providers and commissioners of dementia care can draw on.

The inquiry requested evidence from a variety of stakeholder groups, including people with dementia, carers, health and social care professionals, care home and home care providers, academics, regulators and trade bodies.

These people were asked what they saw as the barriers to achieving quality and cost-efficient dementia care across the UK, and what opportunities there are to develop knowledge-sharing and best practice in this area.

Working group

Members of the inquiry working group, who heard a summary of written evidence received and oral evidence from organisations and individuals in the House of Commons on 15 and 16 March 2011, are as follows:

Chair: Baroness Greengross, Crossbench Peer

Vice-Chair: Hazel Blears, Labour MP for Salford and Eccles

Vice-Chair: David Blunkett, Labour MP for Sheffield, Brightside and Hillsborough

Vice-Chair: Tracey Crouch, Conservative MP for Chatham and Aylesford

Vice-Chair: Tim Farron, Liberal Democrat MP for Westmorland and Lonsdale

Gavin Barwell, Conservative MP for Croydon Central

Baroness Browning, Conservative Peer

Baroness Blood, Labour Peer

Stephen Lloyd, Liberal Democrat MP for Eastbourne

Anne-Marie Morris, Conservative MP for Newton Abbot

Baroness Ritchie of Brompton, Conservative Peer

Lord Walton of Detchant, Crossbench Peer

Acknowledgements

The group would like to thank Alzheimer's Society for its assistance in collating written evidence for the inquiry and organising the oral evidence sessions. We would like to thank Samantha Sharp, Senior Policy Officer at Alzheimer's Society, for the writing of the report together with Tess Saunders and Nicola O'Brien from Alzheimer's Society.

We would also like to thank the witnesses who took part in the oral evidence sessions, as well as those individuals and organisations that submitted written evidence.

Enquiries

Please direct any comments or queries that you may have about this report or about the Group to the Secretariat at appg@alzheimers.org.uk. Alternatively, contact the Chair, Baroness Greengross, at the House of Lords, London, SW1A 0PA.

Executive summary

Summary

The facts about the growing number of people with dementia in the UK and the associated costs are firmly established. It is well known that dementia is a significant and growing driver of demand for health and social care. The cost of dementia in the UK in 2010 was estimated to be £20 billion and this is expected to grow to over £27 billion by 2018. It is also clear that health and social care budgets are under extreme pressure and there is an urgent need to improve the cost-effectiveness of services.

Given the high financial costs of dementia and the human cost of failing to provide good quality support, commissioners and planners will miss a vital opportunity if they do not treat dementia as a priority area for improving cost-effectiveness. The APPG believes there is ample opportunity for using resources more effectively while at the same time improving outcomes for people with dementia.

The evidence in this report demonstrates that many areas have been able to not only achieve better outcomes for people with dementia but also to achieve greater value for money in dementia care, by making changes to service provision or adopting new ways of working. Many of the examples focus on earlier intervention to prevent crises or delay the need for more intensive types of support.

Witnesses were also clear that integrated models of care are necessary. Professionals from across health and social care need to work closely and co-ordinate services to improve the efficiency and quality of dementia services. These findings should be incorporated within the current health and social care reforms, for example, by ensuring resources are focused on prevention and that commissioning is informed by a wide range of views.

The APPG on Dementia considers that there is considerable potential to increase the cost-effectiveness of dementia services, while at the same time improving outcomes for people with dementia. We urge health and social care planners and providers to consider what they can do differently to achieve these ends. Given the considerable burden of dementia, improving the cost-effectiveness of dementia care could make a significant impact on the overall health and social care budget.

Conclusions

Considering the dementia care system as a whole

- 1 It is vital to consider the dementia care system as a whole when working on how to improve cost-effectiveness. Focusing on single areas has been highlighted as a barrier to improving quality and efficiency because the different parts of the system significantly impact on each other. The approach recommended by stakeholders is to consider how the system as a whole can work most effectively and how the different sectors could best work together to support each other. It is important the pressures to make budget savings do not act as a barrier to joint working.
- 2 Staff are much better placed to make a difference to the well-being of people with dementia if they are well-supported and have the attitude and skills necessary to provide good care to people with dementia. They are also likely to be more productive and efficient if they can communicate well with individuals with dementia, identify problems early and know how to most effectively support the person to maintain independence and quality of life. 'Dementia Champions' has worked well as a model of staff development.¹
- 3 Evidence shows that the physical environment can directly impact on a person's functional ability and independence. There is potential for improvements to both cost-effectiveness and well-being, through careful planning and design of the environment, for example, by preventing falls.
- 4 Volunteers have an important role across all dementia care settings in enhancing the quality of care and it would be useful if their numbers could be increased, not least because of the current perception that dementia care staff often do not have the time to provide one-to-one care. The knowledge and experience of people who are living with dementia and who have cared for people with dementia could be particularly useful. There are a number of examples of individuals already giving their time to support others going through a similar experience.
- 5 The low priority that has been assigned to dementia has hampered the development of services for people living with the condition. The available data on the growing numbers of people with dementia and the costs associated with the condition demonstrate the size of the challenge. These data should be used to plan the future development of dementia services, to ensure money is well spent on good-quality, cost-effective services.

1 Dementia Champions act as leaders in good dementia care and advisers to staff in a range of settings.

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- 6 Services and resources in dementia care have long been focused on people with complex needs and those who are facing crises in their situation. This has been to the detriment of early intervention and prevention services. There is evidence that investing in services for people with lower levels of need can prevent crises and the need for costly, intensive services, such as beds in acute hospitals. The support provided by early intervention can also improve the well-being of people with dementia and carers. Investing in community services may lead to savings in the acute sector, therefore joint planning and budgeting is required to encourage the sharing of costs and savings.
 - 7 Although there is a growing evidence base on cost-effective interventions in dementia care, this evidence has not been used as effectively as it could be to improve the quality and cost-effectiveness of services. Improved use of data would also aid the development of a business case for investing in dementia services.

Hospital care

- 8 Hospital care is expensive to provide and hospital stays can have a negative impact upon the symptoms of a person's dementia, as well as putting them at risk of complications such as infection and falls. Changes to the hospital environment can help to improve experiences of hospital stays; there should, however, be greater efforts to prevent inappropriate hospital admissions by investing in community services. This will be both more cost-effective and better for people with dementia.
- 9 Providing a better standard of care in hospitals will reduce the lengths of stay experienced by people with dementia, by avoiding complications and promoting well-being. There are specific aspects of care that could be addressed, including nutritional care and management of delirium, where simple interventions could be highly cost-effective. This requires an informed workforce, which can recognise dementia and understand how to provide high-quality care that meets the needs of people with dementia.
- 10 To facilitate better care, there should be increased use of psychiatric liaison services and joint working between departments to ensure that the care people with dementia receive is based on specialist expertise. There is also scope for greater involvement of appropriately trained and supported volunteers on hospital wards, to enhance the care provided by paid staff.
- 11 Lengths of hospital stay are too often extended for people with dementia beyond their clinical needs, because of their dementia. Improvements to care pathways and better discharge planning will enable earlier discharges, which will result in financial savings. To enable prompt discharge there needs to be

further exploration of models of reablement and intermediate care to establish the most effective ways of supporting people with dementia after discharge, and to prevent inappropriate readmissions.

Community services

- 12 Ensuring the right support is in place is essential to maintaining a good quality of life for the person with dementia and to avoiding a situation reaching a point of crisis, which may require intensive input from services. However, currently fewer than half of people with dementia receive a diagnosis, meaning there is considerable risk that many people are struggling without the support they need.
- 13 There are a number of reasons behind the low rates of diagnosis, including the low levels of public awareness and understanding of dementia. The confidence and skill of some general practitioners in recognising dementia continues to be inadequate. Increasing the length of GP training so that it is equivalent to other specialisms would allow for improved coverage of dementia within the GP curriculum. But local areas should also consider how best to develop ongoing training, for example, brief, targeted sessions run by specialist dementia services at GP practices. This type of intervention may also support GPs as they take on new commissioning responsibilities.
- 14 The process of receiving a diagnosis is a means to an end, not an end in itself. It is a first step to getting a comprehensive package of support in place. It is this package, tailored to the individual's needs and circumstances, which will help people to maintain their quality of life and cope with the symptoms of dementia. There are also number of case studies of services that provide support at times of crises, which have helped to avoid hospital admission and breakdown in family support.
- 15 Evidence suggests people with dementia can benefit from both pharmacological and non-pharmacological interventions and NICE (National Institute for Health and Clinical Excellence) recommends both should be offered from the early stages of the illness. In addition, maintaining people's physical health can help to avoid a decline that could precipitate the need for hospital treatment or residential care.
- 16 There are a number of specific types of services that have the potential to improve quality of life and the overall cost-effectiveness of dementia services. These include day centres and services that enable people to carry on with interests and hobbies. Support that enables carers to carry on caring for people at home is also essential. This should include day and night respite care, as well as information and education.

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- 17 Peer support – both for people with dementia and carers – was also valued and recommended. The quality of the services provided is of paramount importance. Individuals reported receiving poor-quality services that were wasteful and of no benefit, sometimes with potentially harmful results.
 - 18 The ability of a ‘key worker’ system to improve the quality and cost-effectiveness of care was supported by research findings, as well as the views of professionals and people living with dementia. The co-ordination of the disparate parts of the dementia care system would be welcomed by carers and people with dementia, who find the current system confusing and difficult to navigate. The care management role could be taken on by a range of professionals, depending on the individual circumstances of the person with dementia.
 - 19 Although personal budgets have been found to be very helpful for some individuals, there is little evidence that they would help everyone at the moment. Their use is currently not widespread. There are a number of reasons for this, including a lack of services for people to purchase. The market will need to be developed if personal budgets are to be most effective, so that choice is available. However, it is unlikely that increased use of personal budgets will be sufficient to stimulate the market; other measures are required.

Care homes

- 20 It is vital that care homes are able to provide a good quality of life for people with dementia, given that most care home residents will have some form of dementia. Well trained and supported staff are essential to the provision of good-quality care. The support for staff must go beyond training sessions and should respond to the stress experienced by care home staff.
- 21 It is important that people living in care homes are not isolated from the rest of the community. Opportunities to get involved in the wider community and inviting non-residents into the home could enable residents to have a wider social network and maintain enjoyable activities. Providing services within the care home to non-residents with dementia could be an effective use of existing resources and encourage the embedding of the care home into the wider dementia health and care system.
- 22 Care homes are a core part of the dementia care system and they must be given the necessary support to provide high-quality dementia care. Care homes can benefit significantly from the support and advice of older people’s mental health teams, particularly in relation to responding to behavioural symptoms. A well supported home could mean reduced use of antipsychotics and avoidance of unnecessary hospital admissions, thus saving costs and improving quality of life.

There are also examples of care homes that work in partnership with local health services to provide much needed specialist support for people with high-level needs, who may otherwise experience multiple moves and hospital admissions.

- 23 Support to enable care homes to provide physical healthcare can help to avoid the financial cost of hospital admission, as well as the cost to individuals' health and well-being. Initial investment may be required, in addition to a willingness to try new ways of working – for example, geriatricians working closely with care homes. However, the benefits of reduced hospital admission could be substantial. Residents' well-being will also be better maintained if their physical health and comfort is well supported.
- 24 A significant proportion of people with dementia will be resident in a care home at the end of their lives. Support for care homes to provide good palliative care can avoid the need to move people to hospitals in their last days. Outreach support teams can enable this to happen. Many people would choose to die in the care home that has become their home, rather than be moved to a hospital, and families may also prefer this. Directing money to facilitate this, rather than to fund hospital admissions, appears to be a more effective use of resources and could also be cost-saving.

Recommendations

1 Better collaboration and integration

The different sectors involved in local dementia care systems must work collaboratively to consider how resources could be used more effectively. A well balanced and integrated approach to providing support for people with dementia requires joint planning and also consideration of how costs and savings can be shared.

2 Sharing expertise

Sharing expertise between the different sectors involved in dementia care can help to improve the quality and cost-effectiveness of services. There are a number of examples of this, many of which have been recommended by national guidelines and strategies. The pressure on budgets makes it increasingly urgent that these ways of working are established. They include:

- hospital psychiatric liaison teams
- care home outreach teams
- palliative care outreach teams.

3 Early intervention

There must be a clear focus on early intervention in dementia. This is both cost-effective and likely to improve the quality of life of both people with dementia and their carers. An ‘invest to save’ approach may be required, but it is vital that a long-term perspective is adopted, given the potential gains of focusing on early intervention.

4 Improved co-ordination

Improving the co-ordination of dementia services presents an opportunity to improve outcomes for people with dementia and also increase the efficiency of services. The Group calls for:

- increased use of key workers to act as a single point of contact and a co-ordinator of care (which professional takes on this role should depend on the circumstances of the individual with dementia, but they must have sufficient authority to instigate change within a person’s care package)
- improved sharing of information and data between different sectors.

5 Training in dementia care

The level of training in dementia amongst health and social care staff is still inadequate, despite the opportunity to improve the quality and efficiency of dementia care. The Group calls for the implementation of the recommendation within the NICE guideline – that all staff working with older people in the health, social care and voluntary sectors have access to training in dementia care that is consistent with their roles and responsibilities.

6 Diagnosis

Rates of diagnosis must increase in order to ensure people with dementia have access to the treatment, services and information that they require in order to live well with the condition.

- The Group calls for ongoing campaigns to raise public awareness and reduce stigma, in order to encourage people to seek help if they are concerned about their memory or other symptoms.
- It is important that general practitioners are given the support they need to respond appropriately to people who are concerned they may have dementia. This includes increasing the length of GP training so that there is scope for including an adequate level of training about dementia within the curriculum.

7 Supporting carers

Carers are the mainstay of support for people with dementia and providing support to help them carry on caring is fundamental to providing a good-quality and cost-effective dementia care service. Good quality respite care is a vital part of carer support and this must include night respite services.

8 Sharing best practice

In order to encourage the uptake of cost-effective services that improve outcomes for people with dementia, the Group recommends that evidence of good practice and potential cost savings is widely shared and acted upon.

1 Introduction and background

1.1 Introduction

Dementia represents a major and growing challenge to health and social care. There are approximately 750,000 people living with dementia in the UK in 2011 and this is set to increase to over a million by 2021. The financial cost of dementia in the UK is currently £20 billion each year.² By 2018 dementia will cost the UK £27 billion a year.³

The huge scale of this challenge is beginning to be better understood, and the profile of dementia on the public and political agenda is high and rising. In the last two years national dementia strategies and plans have been published in England, Wales and Scotland to improve the quality of life for people with dementia and their carers. A dementia strategy for Northern Ireland is currently in latter stages of development. These strategies are described below.

But at the same time there is significant evidence that public resources for dementia are still not being deployed effectively and are not delivering good outcomes for people with dementia and their families. A series of reports in recent years from the National Audit Office (NAO) and Alzheimer's Society, as well as others, has shown that health and social care services are struggling to provide good-quality care for people with dementia, despite the increase in awareness and in government priority.

The National Dementia Strategy for England (NDSE)

The Department of Health launched the first ever National Dementia Strategy for England in February 2009. It was published following a series of reports from the National Audit Office, Alzheimer's Society and the APPG on Dementia. All these reports highlighted growing evidence that dementia care services were not sufficiently supporting people with dementia and carers to live well, or making the best use of money spent.

The National Dementia Strategy for England aimed to radically transform the quality of life for people with dementia and their carers in the next five years,

2 Alzheimer's Society, Dementia UK, 2007

3 King's Fund, Paying the price, 2008

setting out 17 recommendations that the government wants the NHS, local authorities and others to take to improve dementia care services. The recommendations are focused on three key themes of:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia.

The government announced an extra investment of £150 million to support local services deliver the strategy. More information on the strategy is available from <http://www.dh.gov.uk/en/SocialCare/NationalDementiaStrategy/index.htm>

The coalition government has stated its commitment to continue work to implement the Strategy and published a revised implementation plan in 2010.⁴

Dementia Action Plans for Wales

In Wales a decade-long review of social services published in 2009 found gaps in the provision of services for people with dementia, from intensive specialist care through to day care and respite services.⁵

In September 2009 the Welsh Assembly Government consulted on the draft National Dementia Action Plan for Wales paper produced by the Task and Finish Group established by the Minister for Health and Social Services. Following that consultation four priority areas were identified.

In July 2010 the Welsh Assembly Government published its plans to improve care and support of people with dementia and their families in Wales. These plans specify the objectives, actions and timescales relating to the four priority areas:

- improving service provision through better joint working across health, social care, voluntary sector and other agencies
- improving early diagnosis and ensuring timely interventions
- improving access to information and support for people and ensuring greater awareness and advocacy services

4 Department of Health, Quality outcomes for people with dementia, 2010

5 CSSIW and Wales Audit Office, Reviewing social services in Wales 1998–2008: Learning from the journey, 2009

- improving training for those delivering care.

Welsh Assembly Government announced additional funding of £1.5 million each year to support and implement the action plans. There has also been an additional £400,000 one-off funding to improve training and information on dementia. More information on the plans is available from <http://www.wales.nhs.uk/healthtopics/conditions/dementia>

The National Dementia Strategy for Scotland

A Scottish Dementia Strategy was published in June 2010. It aspires to deliver world-class dementia care and treatment in Scotland within existing budgets. Local dementia strategies are to be produced by health and social care partners. The strategy identifies five key challenges and sets two key priorities.

Challenges:

- Fear of dementia means that people delay in coming forward for diagnosis.
- Information and support after diagnosis for those with dementia and their carers is poor or non-existent.
- General healthcare services do not always understand how to respond well to people with dementia and their carers, leading to poor outcomes.
- People with dementia and their carers are not always treated with dignity and respect.
- Family members and people who support care for people with dementia do not always receive the help they need to protect their own welfare to enable them to go on caring safely and effectively.

Two key priorities:

- 1 Work to improve the support and information that people with dementia and their carers receive following diagnosis.
- 2 Work to improve the response to dementia in general hospital settings, including alternatives to admission and better planning for discharge.

The Scottish Government is establishing a monitoring framework to track change and improvement in dementia services both nationally and locally. There is a commitment to review the Strategy by June 2013. More information on the strategy is available from: <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia>

The Northern Ireland Dementia Strategy

The need for a strategic approach to dementia was clearly indicated by the Bamford Review of Mental Health and Learning Disability. The review comprises a number of interlinked reviews relating to policy, practice and legislative reform in Northern Ireland. The report – Living fuller lives – focuses on the mental health of older people, including dementia.

The Northern Ireland Assembly Executive, in its response to Bamford in 2008, committed itself to develop a dementia services strategy for Northern Ireland. Development of the dementia strategy is the responsibility of Department of Health, Social Services and Public Safety (DHSSPS) and a draft strategy was released for public consultation in the summer of 2010.

However, the Assembly Executive failed to publish the dementia strategy before the Assembly was dissolved in preparation for the Assembly elections in May 2011, so it remains to be seen what level of commitment the implementation and funding of the strategy will have in the newly elected Assembly. More information on the Bamford review is available from <http://www.dhsspsni.gov.uk/bamford.htm/>

1.2 Audits on the progress of dementia strategies

In England the 2010 National Audit Office (NAO) report found that, despite some early signs of progress, implementation of the National Dementia Strategy for England (NDSE) was patchy, and it was in need of stronger leadership and improved investment.⁶ The findings of the NAO were supplemented in 2010 by the report from the All Party Parliamentary Group (APPG) on Dementia, which found that two-thirds of PCTs (primary care trusts) analysed were unable to account for their funding under the dementia strategy and had not made dementia a priority.⁷

In Wales the 2011 report Dignified care?⁸ – which looked at the experiences of people with dementia in hospitals – uncovered poor communication with relatives of people with dementia, a lack of integration with psychiatry services, and physical environments that were not suitable for people with dementia. It also showed the great difficulty people have in accessing alternative provision for care after a hospital stay, with significantly prolonged stays for those waiting for residential or nursing home care or care packages.

6 National Audit Office, Improving dementia services in England, 2010

7 All-Party Parliamentary Group on Dementia, A misspent opportunity, 2010

8 Older People's Commissioner for Wales, Dignified Care?, 2011

It recommended better knowledge of the needs of older people with dementia, together with improved communication, training, support and standards of care in hospital wards.

Audits of care in Scotland and Northern Ireland have not yet been carried out. However, the reviews of services that preceded the strategies cited above give the most accurate picture of the current state of dementia care.

At the time of publication there is a range of initiatives and developments in the UK relevant to the delivery of dementia care services. These are described in appendix 1.

1.3 Providing high-quality services in a time of financial constraints

Evidence of poor value for money in dementia services is of increasing concern at a time when the difficult financial climate is putting public services under pressure. Considerable strain is being felt within the NHS in England, as it is committed to deliver savings of £20 billion by 2014. Besides this pressure, the Government's 2010 Comprehensive Spending Review (CSR) set out real terms reductions of 28 per cent in local authority budgets across England over the next four years, which is having an impact on the social care services that they provide.

In the same CSR Wales was given a 7.5 per cent cut to central funding. The Welsh Assembly Government chose to protect its integrated health and social services budget from cash reductions over the three-year period; however the protection is not in real terms and means the NHS must make efficiencies to meet unavoidable increases in costs. This comes against a background in which the NHS in Wales has already saved £850 million over the past four years. The settlement for local government will also provide a level of protection for social services at 1 per cent above the settlement from the UK government.

Northern Ireland's central funding was reduced by 6.9 per cent over four years in the CSR, which amounts to savings of £4 billion over this period. The health budget will increase by £326 million, but this is a decrease in real terms. As the health element for Department of Health, Social Services and Public Safety (DHSSPS) budget is estimated to account for something in the region of 77 per cent of the entire budget, concerns have been voiced that pressure will likely be felt in community care, which could impact on people with dementia.

The Minister for Health estimates there will be a shortfall of £300 million this current year, rising to £800 million in 2014/15, just to maintain services and to meet increased demographic need. DHSSPS officials are working on measures to reduce this significant gap but a detailed savings plan has not yet been produced.

As a result of the CSR, Scotland's block grant is to fall by 6.8 per cent by 2014/2015. The budget for NHS Scotland has since been protected from cuts by the Scottish Government, but inflationary pressures arising from increasing demographic changes, drugs and staff costs will mean that NHS boards in Scotland will need to make a minimum of 3 per cent efficiency savings to break even.

All of this means that across UK there are competing pressures on the NHS and on local authorities to deliver for many different conditions, and dementia is only one area of concern for them.

Nevertheless, there is evidence that focusing on improving dementia services – by improving, for example, early diagnosis and early intervention – can deliver cost savings to public services as well as delivering a better quality of care for people with dementia.

1.4 Aim of report

APPG on Dementia is interested in driving positive change in dementia care services in this difficult economic climate. It is particularly interested in highlighting evidence of opportunities to make the best use of resources and deliver improved outcomes for people with dementia and their carers.

The purpose of this report is to build up a body of evidence that will be of use to commissioners and providers of dementia care everywhere, highlighting what can be done locally to ensure care is both cost-effective and meets the needs of the people with dementia and their families.

1.5 Methodology

The APPG asked health and social care commissioners, care providers, and key stakeholders to set out what they see as the opportunities for making the most of existing resources in the systems while also ensuring quality of life for people with dementia. Copies of the questionnaires sent out to these groups of people are available at alzheimers.org.uk/appg

People with dementia and their carers were also asked to tell the Group what they feel makes a difference to their quality of life and allows them to live well with dementia. This information was collected through a questionnaire and also through focus groups organised by Alzheimer's Society.

As part of its inquiry, the APPG on Dementia has also commissioned a review of research literature, in the UK and internationally, on economic aspects of dementia care, including studies that have examined:

- the costs of dementia care and support
- the cost-offsets from interventions (changes in total and component costs)
- cost-effectiveness (incremental costs and outcomes of interventions).

The literature review is available at alzheimers.org.uk/appg

At one of the inquiry's oral evidence sessions, Professor Martin Knapp, Institute of Psychiatry, King's College London, defined cost-effectiveness in the following terms:

'If a new intervention, which could be a new treatment, care arrangement or policy, is both more effective and less costly than another, then it is reasonably deemed to be more cost-effective. However, it is often the case that a new intervention is simultaneously more effective and more costly. In those circumstances it is necessary for the decision-maker to ask whether the better outcome is 'worth' the higher cost. If the decision-maker considers that it is worth it, then the new intervention could be called cost-effective. In this sense it is necessary to acknowledge that cost-effectiveness is often a value judgement: it requires the decision-maker to make a trade-off, explicitly or implicitly, between what they are willing to pay to achieve better outcomes.'⁹

1.6 Written evidence

The group received over 200 pieces of evidence. A list of organisations that submitted evidence is in appendix 2.

The full collated evidence, including the anonymous responses from people with dementia and carers, can be found at alzheimers.org.uk/appg

1.7 Oral evidence

Members also heard from witnesses at oral evidence sessions on 15 and 16 March 2011. The witnesses who gave oral evidence are listed below in order of appearance.

Professor Martin Knapp, Professor of Health Economics, Director of the Centre for the Economics of Mental Health at the Institute of Psychiatry, King's College

Karen Taylor, formerly Director of Health Value for Money at National Audit Office

9 Knapp M, Personal communication, 2011

and currently independent adviser on end of life care to Marie Curie Cancer Care

Simon Williams, Lead on Dementia for Association of Directors of Adult Social Services (ADASS) and Director of Adult Social Services at the London Borough of Merton.

Dr Daniel Harwood, Consultant Psychiatrist in Memory Services, Clinical Director, NHS Isle of Wight

Leon Smith, Chief Executive, Nightingale House Care Home

Dr Graham Stokes, Director of Dementia Care, Bupa Care Services

David Walden, Director of Adult Services and Regional Development, Social Care Institute for Excellence (SCIE)

Rachel Thompson, Dementia Project Lead, Royal College of Nursing

Dr Helena McKeown, GP and chair of the British Medical Association committee on Community Care

Transcripts of the oral evidence can be viewed at alzheimers.org.uk/appg

2 Considering the dementia care system as a whole

2.1 Introduction

Organisations and individuals were asked for their views on opportunities to save money while ensuring quality of life for people with dementia in hospital, in their own homes and in care homes. Witnesses argued, however, that there are several overarching issues that apply to all sectors.

This chapter first addresses the need to consider the dementia care system and the range of people and services involved in providing dementia care as a whole. It then discusses the range of issues that are relevant to all settings. These include improving workforce training and ensuring the physical environment is suitable for people with dementia. Finally, it looks at some barriers that witnesses identified as hampering the development of good-quality, cost-effective dementia care services.

2.2 Considering the dementia care system as a whole

It was argued that the dementia care system must be considered as a whole if efficiency and quality are to be improved. This comprises family carers, primary and secondary healthcare, and social care services, which will include the voluntary and independent sector.

Changes in one sector can often increase or decrease pressure in another. In addition, people with dementia may receive support from a range of services at any one time. Therefore, it is important to consider the system as a whole, in order to understand how different areas can best support each other and achieve a better quality, more cost-effective service overall. Joint working, planning and commissioning among the range of services involved in supporting people with dementia is vital.

‘Planners find it easier to concentrate on individual projects without adequate overview of the totality of change required. The individual components of a dementia service, ie, community-based awareness raising and reduction of stigma, early identification and diagnosis, peri-diagnostic support, comprehensive case planning, individualised community services, care home services, general hospital services, end of

life services and an academic ethos of education, teaching and research all function as the cogwheels in a watch mechanism. Failing to provide one or doubling the size of one, lead to the watch as a whole not working. A similar approach is required if well balanced, well integrated dementia services are to be developed in future.

(Royal College of Psychiatrists,
Faculty of Old Age Psychiatry, written evidence)

Rather than separate the identified opportunities under the headings suggested, we've taken the 'whole system' approach ... Our reasoning is that many people with dementia live in one setting but also receive significant services from primary care, secondary care, care homes and elsewhere. There is evidence of this in recent analysis by Bupa Health Dialog, showing people with dementia using health and social care services extensively but without the knowledge of primary care.'

(Bupa, written evidence)

Karen Taylor, formerly Director of Health Value for Money at National Audit Office, described the savings that were achieved in Lincolnshire by adopting a whole systems approach. This work was done as part of the National Audit Office study into dementia, published in 2007¹⁰:

'There is a good practice case example of a whole economy approach to identifying and dealing with dementia, which was in Lincolnshire that we did with a group called the Balance of Care Group. They've taken that forward with Lincolnshire. Lincolnshire has released about £6.7 million from hospital settings to invest in supporting services.'

Several organisations pointed to the Joint Strategic Needs Assessment (JSNA) as providing an opportunity for comprehensive and integrated assessment and planning. The National Council for Palliative Care (NCPC) pointed out:

'Dementia and end of life care both cross health, social care and housing sector boundaries and rely on input from a wide range of statutory, voluntary sector and independent providers. Commissioning must look at the whole range of people's needs and respond accordingly. The JSNA is essential to avoiding duplication and recognising gaps.'

Witnesses discussed how spending in one sector often results in savings in another sector. For example, investing in good community services may result in savings to

10 National Audit Office, Improving services and support for people with dementia, 2007

the acute sector through reduced hospital admissions. This should provide further incentive for the different sectors to work closely and plan how costs and savings can be shared. However Bupa explains that this is not always the case (also discussed in section 2.4.2):

‘However, one barrier transcends all of these and that is the continuing failure in many areas to take an integrated, ‘whole system’ approach to health and social care. This approach is vital to the achievement of the best and most cost-effective dementia care because otherwise, an investment in one part of the system will be seen as a burdensome cost because the expected savings are realised elsewhere in the system (most commonly in secondary care).’

(Bupa, written evidence)

While witnesses shared the view that joint working was vital for the development of cost-effective dementia services, they also highlighted that it did not happen routinely. Dr Daniel Harwood explained that cuts in funding are acting as barriers to effective joint working:

‘Health and local authority, rather than working together, there’s a danger that they’re going to pull apart. Now, it’s not happening everywhere, but it’s certainly happening where I work. The local authority wants to pull the funding from the memory service and move their workers out into generic teams. Now, there may be some advantages to that, but for the people with dementia and their carers there’s a lot of disadvantages and that’s a real worry for me.’

(Dr Daniel Harwood, NHS Isle of Wight, oral evidence)

Simon Williams, of Association of Directors of Adult Social Services (ADASS), urged that the changes that will be brought by the government’s Health and Social Care Bill (see appendix 1 for more information) should be seen as an opportunity to instigate better joint planning and co-operation:

‘We would just really want to sit down with our health colleagues amidst all the changes and say, “Let’s really look at where money is leaking out of our shared system, using evidence of public health and all that stuff and let’s really, really focus on four or five things where we can move money around to make a difference” ... I think again dementia would be a really good example of where, working with our health colleagues and provider trusts, there are already good examples of how you can save a lot of money in integrated services and mental health trusts.’

(Simon Williams, ADASS, oral evidence)

CASE STUDY**Whole systems approach – The Forth Valley Dementia Project**

The Forth Valley Dementia Project illustrates how multi-disciplinary co-operation can improve the provision for dementia care. In 2007, the Dementia Services Development Centre at the University of Stirling secured a Scottish Government grant to undertake a dementia improvement programme in the Forth Valley area.

The aims of the one-year project were:

- to determine the needs of people with dementia
- find out what services were available
- devise ways of improving the provision of care.

The 12-month pilot project provided a clear focus for service development, together with information, education and the tools and techniques to implement change across the whole system of dementia care. It took place across Clackmannanshire, Falkirk and Stirling Council areas. Therefore, three separate local authorities were working together with their health colleagues in primary and secondary care, and also with third sector organisations. The project ended in March 2008.

The project was launched with a one-day convention at which a wide range of staff who routinely work with people with dementia were asked to identify their existing challenges and suggest actions to deal with them. The ideas gathered provided the basis of an action plan, which translated into a range of activities, all targeted at improving services for people with dementia in the Forth Valley area. Some of the ideas had no cost implications, and some were paid for through project funds, while others were subsidised by participating partners or from other sources.

Examples of changes made include:

- A nurse at Bonnybridge, a small community hospital, realised that some of her colleagues already had some 'specialist' skills in carrying out interventions or investigations for people with dementia. As part of the nurse's leadership development through the project, she created a register so that everybody knew who these nurses were and when they were on duty. Previously, patients had to travel to a clinic or other hospital for a procedure like having blood taken. This took up staff time and was confusing or disturbing for the patient. Now patients can see a nurse from a different department within the same hospital. This has saved time and

money for nurses and patient transport services, while improving patient care.

- Alzheimer's Scotland provided a catalogue of all the services available to people with dementia in each council area. There was collaborative work between the university and health and social care staff to update and distribute the information.
- A training course has been developed to help relatives, carers and care support workers in the Falkirk area understand dementia better and improve their interaction with people with dementia.
- People with dementia took part in the nurse education programme. There is now a commitment to ensuring that people with dementia are involved in future courses.
- At one care setting in Forth Valley offering day and residential care a small group of people with dementia and their relatives took part in a pilot to create life story books. As a result of this project, the Scottish Government is funding the creation of 1,000 life story books across Scotland. These can be taken and used in whichever care setting the person with dementia lives in.

Outcomes:

- Almost half (47 per cent) of staff in Forth Valley who responded to a survey said they felt more confident in caring for people with dementia, and a further 51 per cent said they felt confident.
- Examples of good practice were being implemented more widely, and resources made available.
- System changes have taken place, and there is an indication that more partnership working is taking place across organisations. For example, one of the first care home liaison services in the UK was set up. A consultant psychiatrist of old age and hospital nurse worked together to support a group of care homes in the independent sector, and reduced the number of emergency admissions from those care homes to the hospital to zero, over one winter, from a previous number of over 40.
- Personal testimonies from organisations such as the police, churches, libraries and voluntary organisations, as well as members of the public, show they feel that their knowledge of how to support people with dementia in Forth Valley has improved.
- The Forth Valley project acted as a pilot project for a similar two-year project that has since taken place in the Lothian area, over three local authority areas. During that project the number of patients diagnosed

increased by 30 per cent, and many staff have increased their knowledge about and confidence in caring for people with dementia.

Further information

More information about the Forth Valley Dementia Project can be found at http://dementia.stir.ac.uk/Forth_Valley_Dementia_Project_Project1

Conclusion

It is vital to consider the dementia care system as a whole when working on how to improve cost-effectiveness. Focusing on single areas has been identified as a barrier to improving quality and efficiency because the different parts of the system significantly impact on each other. The approach recommended by stakeholders is to consider how the system as a whole can work most effectively and how the different sectors could best work together to support each other. It is important the pressures to make budget savings do not act as a barrier to joint working.

2.3 Issues of relevance to all sectors and care settings

2.3.1 Support must consider the needs of the individual

Carers and people with dementia were clear that support needs to be tailor-made to suit the individual, so that it more effectively meets their needs. Regardless of the care setting, respondents emphasised the need to see each individual with dementia as a person with a history, specific needs and a range of preferences. Services that consider the individual circumstances and interests of the person were most likely to be of value to the person with dementia and therefore be a good use of resources.

‘Day care provides a respite for the carer but is not necessarily welcomed or accepted by the sufferer. If day care were structured to pick up the pre-dementia interests of the sufferer it would be more readily accepted; eg, if the sufferer had previously been artistic or a cook, classes on basic art or cuisine would seem more natural.’

(Carer, written evidence)

‘In my experience with both my mother and mother-in-law the main difficulty is a ‘one size fits all’ attitude to dementia and elderly care. Both ladies in question were not particularly clubbable so the “let’s all go on a bus to the day centre”, was not popular. It is important to gain an insight into the personality either through talking to the person with

dementia or their families to see what activity might be acceptable.’

(Carer, written evidence)

Personal budgets have helped some people to achieve a more tailored care package, but the evidence for their effectiveness is mixed (see section 4.3.8).

2.3.2 Staff training

Witnesses said that improving the training of all staff working with people with dementia would improve the quality of care provided and also enable staff to provide support in a more efficient and productive manner. Many carers pointed out that poor-quality care, provided by untrained and unsupported care staff, was not a good use of limited resources. Investing in training and developing staff would help to improve outcomes for people with dementia and carers, as well as ensuring better value for money when purchasing care services:

‘Better training for social workers etc: if the problem is dealt with first time it costs less in time and wages than the present system where it takes multiple phone calls and visits to solve the simplest request.’

(Carer, written evidence)

‘It seems clear to me that when my wife was in hospital most of the nursing staff failed to appreciate that dementia sufferers need a tailored care system, which was different from the regime which catered well enough for other patients.’

(Carer, written evidence)

Professor June Andrews of Stirling University also explained how education can help to challenge negative attitudes relating to dementia:

‘The barriers include a sense in some sectors, eg general practice and general hospital staff, that there is nothing that they can do for dementia. Education is the key. There is very little dementia education in the basic preparation of undergraduate or pre-registration health and social care professionals across the board, and this is reflected in the sense of hopelessness often displayed when they meet people with dementia.’

(Professor June Andrews, Stirling University, written evidence)

Specific examples of how staff training can reduce costs and improve outcomes were provided by Skills for Care and by Leon Smith, of Nightingale House Care Home:

‘Critically the standards and qualifications above [referring to a list within Skills for Care’s written submission] will also support the dementia workforce to become more proficient in managing challenging behaviour. Reducing challenging behaviour by supporting the workforce to understand and manage the triggers to such behaviour will reduce incidences of the behaviour. This in turn will reduce the need for antipsychotic medication to be prescribed and will support the coalition government drive to reduce the use of antipsychotic medication. In addition this will improve the job satisfaction levels of the workforce supporting people with dementia, because there will be reduced exposure to challenging behaviour.’

(Skills for Care, written evidence)

‘I was at a meeting recently of our clinical governance group and I was astounded at the amount of money that is being spent on food supplements, with GPs prescribing food supplements simply because people were losing weight and it seemed the easiest thing to do. But if more people were trained in how to communicate with people with dementia, if they understood the nutrition and hydration issues, we wouldn’t need to be spending so much on food supplements, which cost an absolute fortune.’

(Leon Smith, Nightingale House Care Home, oral evidence)

A number of witnesses pointed out that as well as increased staff training, the value of good-quality dementia care staff should be recognised by increased wages and better support for staff.

‘I have already stressed the importance of training for carers, either those working for social services, voluntary bodies or care homes, but I should also say that if such staff are properly trained and the work they do properly acknowledged, both their status and pay should reflect this. When caring and carers get the respect that is deserved the result should be more efficiency, better work and the saving of money.’

(Carer, written evidence)

A number of respondents highlighted the usefulness of ‘Dementia Champions’, who act as leaders in good dementia care and advisers to staff in a range of settings:

‘Having Dementia Champions on the ward/care home floor who were available at all times to provide support and model good ways of caring for someone with dementia to other less knowledgeable staff is a way of improving care and hence quality of life for the client. At the same time

money will be saved because there will be fewer complaints and less staff turnover because of greater staff satisfaction.’

(Dr Amanda Thompsell, St Thomas’ Hospital, written evidence)

Conclusion

Staff are much better placed to make a difference to the well-being of people with dementia if they are well-supported and have the attitude and skills necessary to provide good care to people with dementia. They are also likely to be more productive and efficient if they can communicate well with individuals with dementia, identify problems early and know how to most effectively support the person to maintain independence and quality of life. ‘Dementia Champions’ has worked well as a model of staff development.¹¹

2.3.3 Environment

Improving the care environment to ensure it is suitable for people with dementia can help to improve outcomes for individuals and reduce the risk of avoidable deterioration in abilities and the associated costs.

‘It is clear that the wrong environment can have a negative impact, particularly on somebody who has dementia and also delirium. Therefore without costing a lot of money, ensuring that there is adequate signage in the care home/hospital setting for such things as the toilet, will improve quality of life, potentially reducing falls and saving money. This could also improve the chances of somebody of remaining continent.’

(Dr Amanda Thompsell, St Thomas’ Hospital, written evidence)

Professor June Andrews of Stirling University pointed out that ensuring the environment was supportive of people with dementia and that technology was available to help people maintain abilities could help to reduce staff costs:

‘The cost of care in care homes is significantly weighted towards the cost of staff, and money can be saved by the use of assistive technology and careful design of care homes’.

Stirling University’s Dementia Service Development Centre presented many examples of evidence-based materials that demonstrate the effectiveness of improvements in design, including books on lighting, the acoustic environment, balconies and outside places, and a design audit tool.

¹¹ Dementia Champions act as leaders in good dementia care and advisers to staff in a range of settings.

The College of Occupational Therapists wrote that, ‘Occupational therapists can assess and recommend practical changes, such as improved lighting, which can make a significant difference to the functional ability of a person with dementia and can reduce the risk of falls.’

The King’s Fund discussed its ‘Enhancing the healing environment’ programme, which is working with 22 NHS trusts to improve the care environment for people with dementia. Projects have found that ‘an environment specifically redesigned with input from people with dementia, their carers and staff, can... reduce the incidence of agitation and challenging behaviours, encourage meaningful activities, encourage greater carer involvement as well as improving staff morale, recruitment and retention all of which contribute to a reduction in overall service costs.’¹²

Conclusion

Evidence shows that the physical environment can directly impact on a person’s functional ability and independence. There is potential for improvements to both cost-effectiveness and well-being through careful planning and design of the environment, for example, by preventing falls.

2.3.4 Volunteers

Many witnesses felt that volunteers could be instrumental in improving the quality and efficiency of dementia care in a range of settings. Volunteers with experience of living with dementia or caring could be particularly helpful.

A range of different volunteer roles was suggested. For example, it was argued that often services are not able to provide the level of one-to-one support that is required for really excellent care. Volunteers could address this gap by involving people with dementia in activities, social engagement or other occupation, and they could assist with one-to-one support at mealtimes in hospitals or care homes:

‘Train volunteers, eg, WRVS, to help at mealtimes and with activities that will keep a person with dementia occupied so that they are less demanding on medical staff (eg, help to prevent wandering, calling out).’

(Anonymous county council, written evidence)

‘My husband (86) is very sociable but also very deaf; he greatly values a one-to-one visit each month but can’t hear in groups. There is a

12 Information about the King’s Fund ‘Enhancing the healing environment’ programme can be found at http://www.kingsfund.org.uk/current_projects/enhancing_the_healing_environment/

considerable need for this sort of flexible provision in which volunteers could be used most usefully.'

(Carer, written evidence)

In the case of Arts and Minds (Cambridgeshire and Peterborough Foundation for the Arts and Mental Health), volunteers supported artists-in-residence who worked with people with mental health conditions in a range of settings on arts projects. The volunteers were mostly students planning a career in nursing, medicine, social work, psychology or arts therapies and therefore gained valuable experience through volunteering.

It was also highlighted that people with dementia could get involved in advising and supporting newly diagnosed people. Experienced carers could also support people new to the caring role.

'In Lambeth and Southwark we have been using volunteer ex-carers as peer supporters to provide advice and reassurance to carers, which in turn helps enable them to manage to care for the individual with dementia. The peer supporters also provide support when the person with dementia is newly diagnosed and is being helped to make decisions about their wishes with regards to their future care while they have the capacity to do so.'

(Dr Amanda Thompsell, St Thomas' Hospital, written evidence)

'"Buddy" support by volunteers and peer support allow us to meet people like ourselves.'

(Carer, written evidence)

Other potential roles for volunteers included being involved in the inspection of services and as assistants to social workers, where they were perceived to be over-stretched.

'Social workers have huge caseloads and so their input for the patient is limited or non-existent unless the carer badgers them. There will be a lot of carers of all ages that are experienced without qualifications and these could be used. These people could be under the eye of the social worker or support worker thus lessening their load. In rural areas using people in the community would be beneficial to all concerned. This would cut down the fuel costs and the patient and the carer would probably know them.'

(Carer, written evidence)

Conclusion

Volunteers have an important role across all dementia care settings in enhancing the quality of care and it would be useful if their numbers could be increased, not least because of the current perception that dementia care staff often do not have the time to provide one-to-one care. The knowledge and experience of people who are living with dementia and who have cared for people with dementia could be particularly useful. There are a number of examples of individuals already giving their time to support others going through a similar experience.

2.4 Barriers to the development of cost-effective services

2.4.1 Dementia services assigned a low priority

In addition to the overarching opportunities to improve the cost-effectiveness of dementia services, witnesses identified barriers within the dementia care system that act to prevent the development of good-quality, value-for-money services.

Firstly, it was explained that dementia has historically been a low priority for government and those responsible for planning and commissioning health and social care services. The need to improve dementia services has therefore not been treated with any urgency. The Royal College of Psychiatrists, Faculty of Old Age Psychiatry, explained that:

‘Although money is often cited as the main reason for inability to develop services poor prioritisation of dementia is the real culprit. The increasing number of people with dementia is not news ... What is noticeable in the evidence base referred to here is not only the wealth of national independent reports citing the poor level of dementia care and inadequate information, but also the number of reports with significant economic arguments on why it can be cost effective to improve care (including reports from the National Audit Office and Department of Health). Despite this, service planners and commissioners stick to short-term goals during which dementia services might have a temporary raise in their level of priority only to return to the bottom of the pile once the next problem in primary care or acute care surfaces.’

(Royal College of Psychiatrists, Faculty of Old Age Psychiatry,
written evidence)

Karen Taylor, formerly of the National Audit Office, also argued that the lack of priority given to dementia had hampered the development of services:

‘First of all, is the extent to which dementia is really a national priority given the fact that it wasn’t afforded the same status and support both in terms of financial support and also in terms of the targets that were the way that things [Health and social care services] were delivered up until the last few year. And the lack of those targets meant that it wasn’t being given the same priority by primary care trusts as commissioners, and hospital and others as providers, because they weren’t being measured in terms of how well they were implementing improvements.’

It was stated that the low priority assigned to dementia services has resulted in long-term underinvestment, meaning that problems can now seem insurmountable:

‘The chronic under-investment in specialist services for people with dementia has created a culture where those delivering services feel continuously overwhelmed. Encouragement to undertake small ‘tests of change’ leads to staff dealing with minor operational issues rather than the strategic development of major service overhaul. The concentration on minor operational change allows the key strategy of ‘close beds’ to dominate service provision. A major rethink of how large-scale change management is undertaken needs to occur. This is unlikely to happen by simply stating that primary care is now “in charge”.’

(Royal College of Psychiatry, Faculty of Old Age Psychiatry,
written evidence)

Conclusion

The low priority that has been assigned to dementia has hampered the development of services for people living with the condition. The available data on the growing numbers of people with dementia and the costs associated with the condition demonstrate the size of the challenge. These data should be used to plan the future development of dementia services, to ensure money is well spent on good-quality, cost-effective services.

2.4.2 Failure to focus on early intervention and prevention services

A focus on crisis intervention, rather than investing in prevention services was cited as a barrier. There is evidence that investing in early intervention and prevention services can lead to long-term savings, often through reductions to hospital admissions (see chapter 3). Providing low-level support to carers to carry on caring for the person with dementia at home may help avoid the need for more intensive services. But witnesses argued that the ‘invest to save’ approach was rarely adopted.

‘The social care system... will have to incentivise the provision of early support and thus encourage the development of services. We recognise that there may be considerable resource issues during the lag before potential savings resulting from early intervention are realised, so there is an urgent need to inject short-term funding. However, it is important that a long-term perspective is taken given the potential for early intervention to lead to cost savings and improvements in quality of life.’

(Alzheimer’s Society, written evidence)

‘We’ve heard about the costs, whether it’s £20 billion, as is the case now, in our 2010 report it was £15.9 billion, of which £8 billion were direct health and social care costs. So a lot of money is already being spent on this condition, but it’s being spent too late and at the time when people are in crisis and therefore on the more costly interventions, such as hospital admissions and admission to care homes and those are the things that need to be addressed if we’re going to be able to release resources and provide better support to people earlier on and in the community.’

(Karen Taylor, formerly Director of Health Value for Money at National Audit Office, oral evidence)

‘About the need to invest to save approach – we think there needs to be a shift in terms of investing in primary and community care... It is needed so we can help people avoid hospital admissions, only go into care homes when it’s appropriate and to have better continuity and co-ordination of care.’

(Rachel Thompson, Dementia Project Lead, Royal College of Nursing, oral evidence)

There were concerns that pressures to make savings may further discourage an invest to save approach:

‘There is significant pressure to make savings now, rather than to consider long-term savings by investing in early intervention. In order for reinvestment in services closer to home to achieve whole systems savings, a political consensus needs to be built which argues the case for scaling back acute services.’

(Age UK, written evidence)

‘In the long term changes to social services and the NHS may well be beneficial for patients as we move to more integrated health and social care trusts but in the short term the cuts in social services are already

affecting services in terms of the care packages which are delivered to patients. Our concern is that the local authorities seem to be cutting their preventative services while retaining their crisis intervention services. In our view if there is limited money to spend it should always be spent on preventative services to prevent crises and reduce expensive admissions.'

(Dr Daniel Harwood, NHS Isle of Wight, written evidence)

The fact that investing in prevention/early intervention services can lead to savings within the acute sector discourages local authorities from making such investments, if costs and savings are not shared. Witnesses argued much more has to be done to promote a whole systems approach. It was felt that reforms need to address the need to move funds from the acute sector and crises intervention to invest in community services. Furthermore, local areas must consider how costs and savings can be shared across the different sectors. It was argued that pooled budgets and mechanisms for releasing money from one sector to another could help to address this.

'Achieving the dementia strategy requires co-ordination and support services that work effectively across and within health and social care, but the system itself mitigates against this and if a strategy is to be implemented effectively something needs to be done to address the silo working and the fact that the cost implications or costs savings in one care setting will likely not benefit that setting but will be realised in another setting.'

(Karen Taylor, formerly Director of Health Value for Money at National Audit Office, oral evidence)

David Walden from Social Care Institute for Excellence, argued it might be more difficult to encourage organisations to share any benefits in the current climate of budgetary constraints:

'The third point would be about the improvements we have seen around integration and joint working over recent years. There's a bit of a concern that not only the fragmentation that was referred to, but also that at a time of financial stringency we might see a reversion to silo-based working and cost-shunting across boundaries rather than cost-sharing. And often in social care, for example, investments in social care produce benefits, for example, in reduced hospital admissions, but it's sharing the benefits as well as the investment cost which is important there and there is a concern about that in the current climate obviously.'

(David Walden, SCIE, oral evidence)

Simon Williams, from ADASS (Association of Directors of Adult Social Services), highlighted the potential for the £1 billion of NHS money to support joint working with councils to be used in dementia:

‘I have been saying already that the badged funding that’s around at the moment, this financial year and next financial year, to get local health systems and social care to work together we should absolutely be seeking to use some of that money in the areas of dementia, because the whole point of that funding is essentially to relieve hospital pressures for the NHS and social care needs to make [a] contribution there. If we’re not thinking about how we use that money for people with dementia as part of all that, then we’re missing a real trick.’

(Simon Williams, ADASS, oral evidence)

Conclusion

Services and resources in dementia care have long been focused on people with complex needs and who are facing crises in their situation. This has been to the detriment of early intervention and prevention services. There is evidence that investing in services for people with lower levels of need can prevent crises and the need for costly, intensive services such as beds in acute hospitals. The support provided by early intervention can also improve the well-being of people with dementia and carers. Investing in community services may lead to savings in the acute sector, therefore joint planning and budgeting is required to encourage the sharing of costs and savings.

2.4.3 The evidence base regarding cost-effective services is not utilised

The authors of the literature review highlight reluctance to implement research evidence as a barrier to achieving better value for money in dementia care. They provide the example of cognitive stimulation therapy (CST). This intervention has fairly good evidence supporting its cost-effectiveness, yet it was reported to the authors that only around 10 per cent of PCTs and mental health trusts commission or deliver CST. In addition, the literature review explained that wider implementation of evidence-based interventions often requires investment by independent sector providers (especially care homes), who already feel they are operating within tight margins because of tough fee bargaining by councils.

Karen Taylor, formerly at the National Audit Office, argued that even where examples of good practice exist, they are not taken up in other locations:

‘There are 13 examples of good practice in the two reports we published [National Audit Office reports on dementia], both of which – all of which we were able to put some sort of cost effectiveness on. But what we find is very little dissemination and up take of examples even where there is an evidence base, but as Martin [Professor Martin Knapp] mentioned, the evidence base isn’t as robust, perhaps, as people would like. So that lack of awareness and understanding and the need to raise it and raise awareness amongst all healthcare professionals across all sectors, both health and social care.’

(Karen Taylor, formerly Director of Health Value for Money at National Audit Office, oral evidence)

Bupa argued in its evidence that this was compounded by a lack of data:

‘Without reliable data and sophisticated analytics, it will be impossible to construct a robust business case for the investment required in order to release substantial net savings.’

Conclusion

Although there is a growing evidence base on cost-effective interventions in dementia care, this evidence has not been used as effectively as it could be to improve the quality and cost-effectiveness of services. Improved use of data would also aid the development of a business case for investing in dementia services.

3 Hospital care

3.1 Introduction

At any one time, up to one quarter of hospital beds are occupied by people with dementia over 65 years of age.¹³ Yet research shows that there is unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland.

People with dementia stay far longer in hospital than other people admitted for the same procedure, often unnecessarily. The National Audit Office study in Lincolnshire found that more than two-thirds of people with dementia no longer needed to be there.¹⁴ This represented a total of £6.5 million that could be invested more appropriately in other services.¹⁵ The King's Fund extrapolated from this finding that over the whole of England, this would equate to more than £300 million that could be allocated more productively.¹⁶

As a whole, the evidence submitted to the inquiry acknowledged that hospital care is expensive to provide, and that some of the money currently spent on caring for people with dementia in hospital could be more effectively invested elsewhere in the care system, helping to prevent hospital admissions and enable earlier discharges. There was also a need to improve the quality of care on hospital wards, which could reduce lengths of stay, so that resources can be used more cost-effectively.

As discussed in chapter 2, hospital care is part of an interconnected system of care, where changes in one sector can often increase or decrease pressure in another. Witnesses said that re-examination of the way that hospital care is provided is a key issue to a whole-systems approach, because:

‘The most opportunity to unlock money is in hospital care and together we have to find a way of moving some of that money across into not just non-hospital care but non-health care.’

(Simon Williams, ADASS, oral evidence)

13 Alzheimer's Society, Counting the cost, 2009

14 National Audit Office, Improving services and support for people with dementia, 2007

15 £6.5 million is the community's total expenditure on all patients between April 2006 and January 2007 on excess bed days under Payment by Results. A significant proportion of this spend is on patients with dementia.

16 King's Fund, Mental health and the productivity challenge, 2010

Witnesses also identified the need to change hospital care as an urgent challenge, as the current design of hospital care no longer reflects the population it serves. It was emphasised that:

‘The population’s aged, the incidence of dementia has risen, so more of these people come into hospital. So we’ve got to fundamentally change the way that we operate hospital care, haven’t we... almost the specialty now needs to be the young people with an acute problem and the fact that geriatric medicine is a sub-speciality, well, that seems very outdated. Geriatric medicine is what medicine is now.’

(Dr Daniel Harwood, NHS Isle of Wight, oral evidence)

Witnesses concluded that it is vital that people with dementia do not get admitted to hospital unnecessarily, and that when they do spend time in hospital they receive high standards of care. Reducing the numbers of people with dementia being admitted to hospital and the lengths of time they spend as inpatients in expensive hospital care will not only result in savings, but could also improve outcomes for people with dementia. This chapter discusses how this might be achieved.

3.2 The hospital ward as an unsuitable environment for a person with dementia

There was clear agreement in the evidence that the hospital ward is neither the best care setting for most people with dementia, nor the most cost-effective way to provide care. The evidence stressed that:

‘The key aim for hospitals in the future should be to keep people out of hospital wherever possible and this particularly applies to people with dementia, who are especially prone to the complications of admissions such as infection, delirium, falls, etc.’

(Dr Daniel Harwood, NHS Isle of Wight: written evidence)

Evidence emphasised that the hospital ward was ‘sometimes physically damaging, often confusing and [a] very disempowering environment’ (Barchester Healthcare, written evidence), and ‘bad for people with dementia for all sorts of reasons’ (Dr Daniel Harwood, NHS Isle of Wight, oral evidence).

It was pointed out that the acute clinical setting can be disruptive for people with dementia and have a negative impact upon their condition as the clinical and institutional nature of hospital stays upsets people’s routines, and can have a negative effect on the symptoms of dementia.

Evidence highlighted that the physical environment in hospitals can directly impact on a person's ability and independence. Making changes to the ward could be a cost-effective way of improving the experience of people with dementia while in hospitals as:

'People with dementia can find hospitals confusing and frustrating. Simple changes to the layout of a ward can make hospital easier to navigate, reducing stress, freeing up nursing staff and improving patient safety. Examples of these simple changes include colour-coded doors, simple signs and easy-read menus.'

(Age UK, written evidence)

This has been discussed further in section 2.3.3.

3.3 Avoiding unnecessary hospital admissions

Much of the evidence focused on how to avoid hospital admissions in the first place. Helping to avoid hospital admissions requires having sufficient community support available to people with dementia and their carers, preventing the crises that often force hospital admissions. Such community services should be responsive to need and available 24 hours a day.

In written evidence Dr Chris Clough, an adviser to the Department of Health, suggested that, 'A crisis hospital admission should be seen as a failure of the system'. Despite this, currently:

'The first way we waste money is we force people into crisis and then we manage crises very poorly, whether it's the carer's crisis, an illness, whatever it may be.'

(Simon Williams, ADASS, oral evidence).

It was also emphasised that community services must include adequate support for carers, as the support they provide to the people they care for is key to avoiding crisis admissions to hospitals. The role of community services is discussed further in chapter 4.

Conclusion

Hospital care is expensive to provide and hospital stays can have a negative impact upon the symptoms of a person's dementia, as well as putting them at risk of complications such as infection and falls. Changes to the hospital environment can help to improve experiences of hospital stays; there should, however, be greater efforts to prevent inappropriate hospital admissions by

investing in community services, for example carer support. This will be both more cost-effective and better for people with dementia.

3.4 Improving standards of hospital care

The evidence submitted by people with dementia, carers and organisations identified the quality of care provided to people with dementia in hospital as an area for attention. A carer argued in written evidence that, ‘length of stay for people with dementia in the acute hospital is typically extended, sometimes hugely so, by inappropriate dementia care’.

Many of the responses referred to Alzheimer’s Society Counting the cost report, which found unacceptable variations in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland.¹⁷ Age UK also pointed to the recent Health Service Ombudsman for England’s report on hospital care,¹⁸ which was based on the findings of ten independent investigations into complaints about NHS care for people over the age of 65 across England. The Ombudsman drew attention to the stark contrast between the care people received and the stated values of the NHS; yet in these ten cases there had been a failure to meet even the most basic standards of care. Age UK said the Ombudsman’s report must act as ‘a wake-up call for hospitals’ to improve the standards of care for older people, a large proportion of whom have some form of cognitive impairment or dementia.

3.4.1 A trained and knowledgeable workforce in hospitals

Much of the evidence recognised that hospital staff do not have enough understanding or awareness of dementia and need to be properly trained in how to provide care for people with dementia, in order to reduce length of stay. There was consistent agreement that,

‘...people who have dementia are not understood therefore hospital stays can become prolonged.’

(National Care Forum, written evidence)

and that,

‘With the growing number of dementia sufferers a greater proportion of the nursing staff need to be trained to cope with them’.

(Carer, written evidence)

17 Alzheimer’s Society, Counting the cost, 2009

18 Health Service Ombudsman, Care and compassion?, 2010

The Royal College of Psychiatrists pointed out that despite the growing number of people with dementia being admitted to general hospital wards, basic dementia awareness training was mandatory for staff in less than five per cent of hospital sites.¹⁹ This results in a situation where,

‘Staff in general hospital units frequently do not have training in the management of people with dementia and see the problems presented as either overwhelming or “not requiring their care”.’

(Royal College of Psychiatrists,
Faculty of Old Age Psychiatry, written evidence)

As discussed in chapter 2, investing in training and developing staff would help to improve outcomes for people with dementia, as well as ensuring better use of resources by reducing lengths of stay. Currently it appears that the numbers of hospital staff receiving training on dementia is limited, with consequences for the standard of dementia care provided on general hospital wards.

3.4.2 Improving basic care

Improving basic care provided on hospital wards was identified as an area that could significantly improve the experience of a hospital stay and reduce the number of complications and the lengths of stay. Examples of basic care include ensuring that people with dementia have regular meals and are given any necessary medication.

Specific aspects of care that required attention included the need to improve pain recognition, delirium and nutritional care. This would not only improve quality of life for people with dementia, but could also reduce complications and some behavioural symptoms that are sometimes poorly managed in a hospital environment.

A number of written submissions focused on the need for improvements in the assessment of nutritional needs, including evidence from Age UK, which referred to its Hungry to be Heard report that highlighted the numbers of older people who were going hungry while in hospital.²⁰ Evidence submitted by the British Specialist Nutrition Association Ltd (BSNA) drew attention to existing estimates of how better nutritional care could result in significant savings. For example, the National Institute for Health and Clinical Excellence (NICE) has estimated that the delivery of better nutritional care is the fourth largest potential source of cost savings for the NHS.²¹

19 Royal College of Psychiatrists’ Centre for Quality Improvement, National Audit of Dementia Care in General Hospitals, 2010

20 Age Concern, Hungry to be heard, 2006

21 National Institute for Health and Clinical Excellence, Nutrition support in adults, 2006

The British Association for Parenteral and Enteral Nutrition (BAPEN) has estimated that a saving of one per cent of the annual healthcare cost of malnutrition would amount to annual efficiency savings of £130m (this figure relates to the whole population, not just people with dementia).²²

BSNA's evidence also pointed to simple cost-effective interventions that could improve nutritional care, such as red-tray schemes, protected meal times, detailed care plans that include required nutritional interventions, and systematic screening and monitoring to ensure that a person's nutritional needs are being effectively managed. It also recommended full implementation of the NICE (2006) clinical guideline on nutrition support in adults to ensure people with dementia are better nourished, and reduce complications such as secondary chest infections, pressure ulcers and cardiac failures.²³

Programmes for preventing delirium, a common complication of dementia, were highlighted in the evidence submitted by the British Geriatric Society, who pointed out that although patients with dementia are at high risk of delirium, both senior non-clinical hospital managers and clinicians often lack basic knowledge of dementia and delirium, and many hospital staff see these conditions as being the remit of geriatrics and/or psychiatry, rather than a major part of mainstream acute care. They pointed out that there are virtually no UK hospitals with systematic delirium prevention programmes, even though delirium is a serious complication of dementia and adds to risk of death and new institutionalisation. Thus 'addressing delirium prevention and care of delirium if it arises is one of the urgent priorities in hospital care, because prevention is cost effective, and because delirium is so common (one in eight hospital patients)' (British Geriatrics Society, written evidence).

The BMA also highlighted reducing the use of antipsychotic drugs as key to improving care. They argued that reducing the number of inappropriate prescriptions would 'inevitably' lead to cost savings.

Conclusion

Providing a better standard of care in hospitals will reduce the lengths of stay experienced by people with dementia, by avoiding complications and promoting well-being. There are specific aspects of care that could be addressed, including nutritional care and management of delirium, where simple interventions could be highly cost-effective. This requires an informed workforce which can recognise dementia and understand how to provide high-quality care that meets the needs of people with dementia.

22 British Association for Parenteral and Enteral Nutrition, Combating malnutrition, 2009

23 National Institute for Health and Clinical Excellence, Nutrition support in adults, 2006

3.4.3 Improving the diagnosis and identification of dementia

The need to better identify hospital patients who have dementia was also highlighted. Age UK's response referred to evidence that over 50 per cent of dementia in acute settings is unrecognised. Recognising dementia is important because it ensures that patients' care pathways are clear and that they receive appropriate treatment and care.

Despite this, a diagnosis of dementia can be overlooked in hospitals, as Alzheimer's Society explained:

'Acute hospital staff generally consider it crucial to establish any pre-existing physical conditions in a patient, but mental health screening of older patients who appear confused is not routine and a formal diagnosis of dementia is not seen as a priority. Hospital old age psychiatric liaison teams would help support diagnosis in general hospitals but are not always available and vary widely in their approach and resources. Moreover, evidence from the NAO's Lincolnshire case study suggests that dementia diagnoses may not always be given in hospital, as healthcare staff fear it could be a barrier to discharging the patient to suitable rehabilitation or intermediate care.'

(Alzheimer's Society, written evidence)

Even when a patient has had a previous diagnosis of dementia, hospital staff may not know about the diagnosis. The evidence submitted indicated that the lack of diagnosis or lack of knowledge about a diagnosis, prevents optimal care in hospital and adequate discharge planning. This can result in longer lengths of stay and higher rates of institutionalisation than might otherwise occur.

Examples of work to increase awareness of a diagnosis of dementia included the 'Butterfly Scheme', which runs in several NHS trusts, where a person can choose to have a butterfly symbol displayed to indicate to hospital staff that they have dementia. Staff are trained in how to respond to the butterfly symbol via a five-point plan to ensure that appropriate care is provided.

The Royal College of Psychiatrists also drew attention to examples of work in Leeds and Liverpool to improve identification and management of people with dementia. However, the college emphasised that in isolation such strategies are not an adequate response. What is needed is a more integrated approach, as discussed in chapter 2.

'A close link or integration with community based specialist services would ensure that people with dementia in the community would be highlighted at the point of admission and community staff involved

intrinsically in the discharge planning process. Not infrequently assumptions are made about a person's ability to manage in the community by hospital based staff who have no direct involvement in the provision of care nor in the assessment and management of risk in the community. Consequently, being admitted to hospital has become a risk factor for entry into care and once in care there is usually no return to the community. Close integration of community-based and general hospital based services would assist the improvement of the risk management process described above.'

(Royal College of Psychiatrists, Faculty of Old Age Psychiatrists, written evidence)

CASE STUDY

Screening for dementia: work with surgery/anaesthetic departments – Isle of Wight PCT

In the Isle of Wight, there has been work with the general surgery and anaesthetic departments to carry out screening for dementia, before people are even admitted to hospital. This can happen at pre-assessment clinics, or in the GP's surgery.

If someone is identified as having dementia, it allows there to be individual assessments to decide which type of anaesthetic is most appropriate for a person with dementia. This means that the person can receive targeted interventions, including the use of special anaesthetic agents which might be less toxic and improved analgesia, and allows better discharge planning.

This work is in its early stages and, therefore, there is not yet information about its cost-effectiveness. However, its aim is to avoid the unnecessary complications which can be caused by anaesthesia, and which can result in prolonged lengths of stay for people with dementia. This will allow savings to be made in hospital care.

This work has been possible because there is an anaesthetist who has a special interest in dementia within Isle of Wight NHS. However, the Isle of Wight NHS suggest that all trusts could identify such a lead clinician in the anaesthetic department to be responsible for such work, as this intervention could assist in reducing lengths of hospital stays for people with dementia.

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3.4.4 Greater involvement of dementia care specialists

Greater involvement of dementia care specialists in care on the hospital ward was seen as important in improving the standard of care and in expediting the diagnosis and assessment of inpatients who have dementia.

Many respondents highlighted evidence demonstrating the cost-effectiveness of old-age psychiatric liaison teams in reducing inpatient stays, documented in the NICE Clinical Guideline on dementia²⁴ and in the Royal College of Psychiatrists' guidelines – Who cares wins²⁵.

'With 300 referrals per annum, there is a potential saving of 1,500 days waiting per acute hospital. If only half of these patients' discharge planning were delayed as a result of waiting for a psychiatric opinion, then this would equate to 750 bed days (County Durham and Darlington primary services NHS Trust, 2004).'

(British Medical Association, written evidence)

Two submissions argued that psychiatric or specialist liaison need not necessarily involve large numbers of specialists, for example:

'We have one nurse and one support worker who support the general hospital and provide advice, training, support and guidance to general hospital staff looking after patients with dementia. This can facilitate early discharge.'

(Dr Daniel Harwood, NHS Isle of Wight, written evidence)

However, the Royal College of Psychiatrists explained that despite the evidence demonstrating the effectiveness of liaison services, there remain barriers to their development, chiefly relating to a lack of co-ordinated commissioning, and in particular giving the responsibility for delivering these services to either mental health trusts or general hospitals. This underlined the importance of considering the dementia care system as a whole.

24 NICE and SCIE, Dementia: Supporting people with dementia and their carers in health and social care, 2006

25 Royal College of Psychiatrists, Who cares wins, 2005

CASE STUDY**Hospital liaison in Leeds – Leeds liaison psychiatry service**

The Leeds liaison psychiatry service is a multidisciplinary hospital mental health team based at Leeds General Infirmary, providing a comprehensive service to Leeds General Infirmary, St James's University Hospital and Chapel Allerton Hospital. The team is made up of psychiatrists, psychiatric nurses, an occupational therapist and health support workers, with administrative support. Referrals can be made for any patient aged 65 or over, who is either an inpatient or in the accident and emergency department, where there are concerns about a mental health problem.

The team carries out specialist mental health assessment and follow-up for older people in the general hospital, and plays an important role in care planning meetings in more complex scenarios (particularly involving people with dementia), signposting people with mental health problems and their carers to appropriate community services on discharge. The team meets on a daily basis to discuss referrals, ensuring that all cases are discussed in a multidisciplinary context and a weekly review meeting is held to monitor the progress of patients until they are discharged from the service.

Another important function of the team is to provide training and education for acute trust colleagues of all disciplines and grades in the management of common mental health problems, including a series of sessions on dementia, which focus on person-centred care. This training equips staff with the necessary knowledge and skills to improve the detection and day-to-day management of people with dementia, and, more significantly, challenges the negative attitudes of staff towards people with dementia.

The outcomes of the service confirm the importance of identifying and addressing dementia in the acute hospital setting:

- Up to 500 of the 1,500 referrals seen in one year were people with dementia.
- 90 per cent of hospital referrals were seen the same day, and unplanned admissions with a primary diagnosis of dementia reduced substantially.
- The average length of stay for people with dementia fell by 54 per cent from 30 to 13.9 days, saving 1,056 bed-days per year. Almost half of the people seen by the service were not previously known to mental health services.

There were also suggestions that more joint working across departments within hospitals would be a cost-effective way to improve care quality. The British Geriatrics Society referred to successful examples of this within acute trusts:

‘There are also examples of service redesign in acute trusts, eg joint wards run by geriatricians and old age psychiatrists which, if appropriately designed and managed, should reduce the problems in acute trusts. This means a reconfiguration rather than a huge investment to produce more efficient ways of working.’

(British Geriatrics Society, written evidence)

Joint medical-psychiatric wards could enable the best care for medically sick dementia patients, ending the need for patients to be moved between wards, resulting in poor clinical management and repeated assessments. Evidence submitted by the BMA argued that this could be a more cost-effective way to provide high-quality care for people with dementia who have been admitted to acute hospitals.

3.4.5 Increasing the use of volunteers in hospitals

Additional ideas for improving cost-effectiveness in hospitals included greater use of volunteers and involvement of carers to improve the quality of care, as detailed in chapter 2. Within hospitals, suggestions for volunteer roles included volunteers to assist at meal times and with activities in wards to occupy patients, or to spend time with patients.

The Care Quality Commission (CQC), however, stressed that while using volunteers could enhance the provision of person-centred care, volunteers would have to be appropriately trained and supported. CQC added that increasing the use of volunteers must not be based on assumptions that family carers may take on these roles, and family carers must not be over-burdened by this.

Conclusion

To facilitate better care, there should be increased use of psychiatric liaison services and joint working between departments to ensure that the care people with dementia receive is based on specialist expertise. There is also scope for greater involvement of appropriately trained and supported volunteers on hospital wards, to enhance the care that is provided by paid staff.

3.5 Reducing lengths of stay

Reducing the length of stay in hospital for people with dementia was identified as a key area where savings could be made through improving existing care pathways and discharge planning, as well as accessing care and support in other settings that can enable earlier discharges. Alzheimer's Society summarised the existing evidence about lengths of hospital stay for people with dementia, and the potential scale of savings that could be made:

'There is evidence that it may be possible to reduce the amount of time people spend on hospital wards. The Alzheimer's Society report, *Counting the cost*, found that people with dementia were staying longer in hospital than was expected. Also, when admitted for the same condition, people with dementia stayed longer in hospital than people without dementia. This is supported by published research..

People with dementia staying in hospital longer than expected will undoubtedly place additional financial pressure on the NHS. Alzheimer's Society believes that as a starting point it would be reasonable for hospitals to work towards supporting people with dementia to leave hospital one week sooner than they currently do. Based on the report's estimate that up to a quarter of people in hospital have dementia (25 per cent), it was estimated that savings of over £80 million could be achieved by reducing hospital stay by one week for just four HES codes (fracture of femur, total prosthetic replacement of hip joint using cement, urinary tract infection, transitory ischemic attack (TIA)).

These figures are supported by the NAO (2007) finding that in just one condition (fractured hip), more effective identification, management of care and discharge could produce savings of between £64 and £102 million a year nationally.²⁶ These savings could be reinvested in workforce capacity and development, and community services outside hospital.'

(Alzheimer's Society, written evidence)

3.5.1 Improving care pathways

In order to reduce lengths of stay, care pathways for people with dementia need to be improved so that they work more efficiently. It was indicated that even simple changes to care pathways could be beneficial. For example:

'Integrated care pathways in general hospital units infrequently have a

26 National Audit Office, *Improving services and support for people with dementia*, 2007

check box for dementia in contrast to COPD, cardiac failure, hypertension or other long-term conditions. The addition of a simple box or a simple questionnaire about forgetfulness would undoubtedly raise awareness amongst general hospital staff. Although many units will have a quality standard stating that 100 per cent of people over the age of 65 should have a brief intellectual assessment after admission in many cases less than one-third of patients will actually have this done. The reasons for not doing so include 'at the time the patient appeared lucid'. One wonders how failure to carry out an ECG because 'the patient did not appear in pain' would be interpreted in an audit of medical practice.'

(Royal College of Psychiatrists, Faculty of Old Age Psychiatry,
written evidence)

However, the evidence from Barchester suggested that there may also need to be significant structural change beyond the hospital environment to enable innovation to achieve fully integrated care pathways. This will require:

'...proactive engagement by commissioners with providers and a degree of honesty and trust that must be based not just in the fair market envisaged in the recent health White Paper but in engaged relationships, a continuous exchange of information and conscious construction of strategic partnerships between commissioners and providers. New commissioning arrangements need to be planned with the facilitation of such relationships and a built-in imperative to reduce inappropriate hospital admissions in mind. Joint commissioning across health and social care would be invaluable in this context, binding together responsibilities for managing housing issues and assessment around health, care and support needs generally, allowing for badly needed innovation.'

(Barchester Healthcare, written evidence)

Having a diagnosis of dementia made and communicated was also identified as key to care pathways working well, as discussed in section 3.4.3.

3.5.2 Improving discharge processes

Some of the evidence submitted discussed the need to improve the discharge process to avoid prolonging stays in hospital and unnecessary readmissions. A detailed explanation was given in Age UK's evidence:

'One of the most effective ways to achieve savings in secondary care is to improve the discharge process. Patients with dementia often stay longer in

hospital or are readmitted following a poorly planned discharge. Many patients living with dementia are unable to be discharged due to poor communication with families and with social care practitioners, and a lack of understanding in hospitals regarding the funding arrangements for patients with complex needs including dementia.

Hospitals and local health economies can save money by introducing a more personalised form of discharge planning, where they work closely with local authorities to ensure that people with dementia are given the best opportunity to stay independent and are not automatically transferred to care homes. The Department of Health published a checklist²⁷ for hospitals wanting to improve discharge planning for people with dementia.

None of this can effectively be implemented without input from the individuals affected by dementia and their carers. Hospitals cannot expect to design pathways without them and they cannot hope to treat individuals with care and compassion without asking them what that means to them. People living with dementia and their carers are useful resources and should be treated as such, not as obstacles to care. We recommend that acute trusts put the engagement of patients with dementia and their carers at the heart of their efforts to save money while maintaining standards of care.'

(Age UK, written evidence)

The need for early planning to ensure that the right support can be organised was emphasised in other submissions, as there was agreement that if the right services are not put in place for the individual upon discharge, it can frequently result in further admissions. Discharge planning should include the early involvement of occupational therapists to enable discharge to the person's own home, and early identification of people's preferences about the way their care is provided.

3.5.3 Intermediate care

Many of the responses received discussed models of intermediate care in alternative settings as being a more cost-effective way of providing care, as care in non-acute settings is generally cheaper to provide. This opportunity to make savings was identified in several responses:

'What we're seeing is the wasteful use of many of those billions of pounds tied up in general hospital care when you could argue that's not

27 Department of Health, Discharge from hospital, 2003

where the money would be better spent. You could see that money being utilised far better in step down care arrangements.'

(Dr Graham Stokes, Bupa, oral evidence)

'One significant opportunity to save on the cost of hospital care, while ensuring a good quality of life for people with dementia, is to enable people to leave the hospital environment quickly following illness and to prevent people from going into hospital at all if this is possible. This is achieved by offering appropriate care, support and health interventions for people in their own homes – wherever they live.'

(Housing 21, written evidence)

The provision of intermediate care was discussed at length in many of the written submissions from organisations, as well as in the oral evidence sessions. Key themes were that if intermediate care were made more readily available it could enable quicker discharge from hospital, reduce the number of readmissions, promote independence and result in cost savings as it would be cheaper to provide. It was also argued that people with dementia can benefit greatly from care and support provided in a residential care setting.

Evidence by Roger Davies, Group Chief Executive, MHA, referred to one example of intermediate care that is having positive outcomes: Charnwood House in Coventry, is a partnership between Coventry City Council and the local PCT, which provides 12 intermediate care beds for people with dementia as well as 45 long-term care places. This was designed with the expectation of enabling more older people to return to their own homes rather than stay in hospital or long-term care. It provides specialist assessment and rehabilitation service for people with dementia, reducing waiting lists and delayed discharges from hospital beds, facilitating discharge back into the community wherever possible.

One response identified barriers to the development of intermediate care placements and argued that the development of such services needs to be incentivised in order to facilitate earlier discharges from hospital wards:

'At present many people with dementia cannot access many rehab beds due to their diagnosis, and residential homes often do not have the capacity, (or correct registration) to take people with dementia.'

(Nurse Consultant for Younger People with Dementia,
primary care trust, written evidence)

Professor Martin Knapp also highlighted potential problems in intermediate care placements:

‘I think the difficulty is often that those sort of stepping stones, halfway places, whether it’s to prevent people going into hospital or when they move out, those facilities often become – to use another insensitive term – silted up with people who can’t then move on and so quite often those facilities are not having a throughput – again a not very nice term, but they’re not allowing people to be discharged because we haven’t got the range of support. I think the NHS and local councils are doing fantastic jobs in developing a whole range of new services to try and make the system less clunky so it’s easier to make those moves, but it is difficult sometimes with the financial flows to have the right incentives for those things to be used.’

(Professor Martin Knapp, Institute of Psychiatry, King’s College, oral evidence)

CASE STUDY

Intermediate care – NHS Harrow

Greenview Intermediate Care Unit, Harrow, north-west London, provides rehabilitation to people with dementia and/or delirium in order to give them the best opportunity to return home following an acute hospital admission. The unit is made of 12 individual en-suite rooms and is part of Woodland Hall nursing home. Although the unit serves people with other functional mental illness, most people will have a form of dementia.

Harrow NHS commissions the service in conjunction with London Borough of Harrow.

The service was set up because health and social care agencies were concerned about the number of people with dementia who were being placed into care homes following a hospital admission.

The service has been successful in preventing unnecessary admission to a care home and to the acute hospital. Achievements include:

- More than half (58 per cent) of patients in the first year of operation returned to their own home.
- An average 40 per cent improvement in functional abilities of the patient.

Innovative aspects of the service:

- Different agencies working across boundaries to deliver common goals, including the local PCT, social services, Central and North West London NHS Foundation Trust, HART (an intermediate care provider part of the North West London Hospital Trust), Care UK (care home provider responsible for the unit and providing the daily care and nursing staff), and GP.
- A range of professionals, including a registered mental health nurse (RMN), an occupational therapist (OT), a physiotherapist, a psychiatrist and psychologist, working together with the person with dementia and their carer to tailor the individual's goal-setting and care programme.

Following discharge, Greenview staff will follow up the patients at home to check on progress, and will discharge them from the service when satisfied that the patient is safe and supported.

Further information

Read a full description of the project in Department of Health (2011) Living well with dementia: a National Dementia Strategy – good practice compendium http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

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3.5.4 The need for reablement services

Some of the evidence also discussed the provision of reablement services. Social Care Institute for Excellence (SCIE) defines reablement services as focusing on helping people to learn or re-learn the skills necessary for daily living.²⁸ Reablement is typically a 6–12 week intervention, helping people regain skills for activities such as washing, dressing, cooking and climbing stairs. It may also focus on social reintegration. There is a strong emphasis on occupational therapy, regaining physical ability and ongoing assessment.

Traditionally reablement services have focused on physical reablement, and as a result ignored the potential benefits for people with dementia and their families. It was recognised that this needs to change, and that 'good reablement services are badly needed to enable earlier and safer discharges for many' (Bupa, written evidence).

28 <http://www.scie.org.uk/adults/prevention/reablement.asp>

SCIE's response described ongoing work in this area:

'SCIE is working with reablement teams in five London boroughs, some of which accept all referrals, including people with dementia and those with palliative care needs. It is their view that people with dementia can benefit from a period of reablement. They also maintain that reablement is beneficial for family carers, increasing their confidence and helping them support users with a more 'reabling' ethos. It is conceivable that the benefits to carers could also delay or reduce the need for intensive care and support by avoiding the occurrence of "crisis points".'

(Social Care Institute for Excellence [SCIE], written evidence)

The evidence received suggests that there is significant scope to explore extended access to reablement and intermediate care services for people with dementia to facilitate earlier discharges from hospital, and that these services are likely to be a more cost-effective way of providing care.

Conclusion

Lengths of hospital stay are too often extended for people with dementia beyond their clinical needs, because of their dementia. Improvements to care pathways and better discharge planning will enable earlier discharges, which will result in financial savings. To enable prompt discharge there needs to be further exploration of models of reablement and intermediate care to establish the most effective ways of supporting people with dementia after discharge, and prevent inappropriate readmissions.

4 Community services

4.1 Improving community care services to increase cost-effectiveness

Nearly two-thirds of people with dementia live in private households (the community)²⁹ and many people report that remaining in their own homes is very important to them.³⁰ The mainstay of support for most people with dementia at home is from family carers. The importance of the support that carers provide is demonstrated by research which found living with a carer means that people with dementia are 20 times less likely to enter a care home.³¹

However, people with dementia and carers also emphasise that statutory services are vital in supporting the person with dementia in their own home.³² Good-quality community services are extremely important in providing cost-effective dementia care, because of the potential to support quality of life and reduce hospital admissions and/or length of stay, as well as delaying entry into residential care where appropriate. As well as supporting people with dementia who live alone, community services can provide essential help to carers.

The potential for effective community care services to result in improved quality of life and cost efficiency was demonstrated in the Alzheimer's Society submission. The Society explained that its recent report, *Support. Stay. Save*, gathered evidence on the care and support of people with dementia in their own homes. It found that:

'Respondents perceived that insufficient support results in the exacerbation of the needs of people with dementia and carers, with reported worsening physical and mental health needs. As a result, people with dementia are most likely to be admitted earlier to long-term care and unavoidably admitted to hospital.'

(Alzheimer's Society, written evidence)

Based on the findings of the report the Society calculated that one in ten of the 500,000 people with dementia living at home will go into long-term care sooner than expected because of insufficient support. This is likely to result in 50,000 people who currently live in their own homes going into a care home earlier than necessary.

29 Alzheimer's Society, *Dementia UK*, 2007

30 Alzheimer's Society, *Support. Stay. Save*. 2011

31 Banerjee S, Murray J, et al, *Predictors of institutionalisation in older people with dementia*, 2003

32 Alzheimer's Society, *Support. Stay. Save*. 2011

Delaying these individuals' entry into a care home would result in savings to the NHS and local government of around £72 million for each month of delay.

A range of opportunities for improving outcomes for people with dementia in the community and also improving cost-effectiveness was identified. Below we describe some of the key themes of the evidence presented and also examples of specific services.

4.2 Key themes

4.2.1 Increasing rates of case identification

A key theme identified by witnesses was low rates of case identification. Not enough people are receiving a diagnosis of dementia or being diagnosed early enough. General practitioners (GPs) are now incentivised to establish dementia registers, as part of the Quality and Outcomes Framework. Figures from these registers suggest that only around 40 per cent of people with dementia are currently receiving a diagnosis and being placed on the registers.³³ This percentage varies depending on the primary care organisation. As noted by a number of witnesses, having dementia diagnosed and recognised is a first step to getting a support package in place which supports a good quality of life and reduces the risk of a crisis requiring high-cost interventions.

'The most important thing is to get early diagnosis – when I went to my GP she immediately referred me to the specialist at the dementia unit at my local hospital where I was assessed, had brain scans, diagnosed and started treatment which amazingly has taken away most of the symptoms of dementia (although I do have side-effects). Without the treatment I was struggling to look after myself at home.'

(Person with dementia, written evidence)

'We perceive that early diagnosis enables the individual themselves to adapt and plan. Furthermore, services and treatments and therapeutic interventions can be commenced earlier which we believe slows deterioration, which delays reliance on higher dependence and costly care. We would note the change in NICE guidance regarding the prescription of dementia medication to be extended to people in early dementia as this was considered to achieve cost saving in care costs.'

(The ExtraCare Charitable Trust, written evidence)

‘Approximately 40 per cent of people living with dementia in the UK have received a diagnosis and are thus known to the NHS. The remainder are part of a high-risk group, but that risk is not being managed because they are not known to the system. As a consequence, they are much more likely to present with health needs only when a crisis has occurred and consume very costly services in A&E or as an in-patient admission. A small study reported in 2010 that relatively minor health issues and social distress were precipitating hospital admissions and that nearly one-third of patients were only diagnosed with dementia after an admission.’

(Bupa, written evidence)

Conclusion

Ensuring the right support is in place is essential to maintaining a good quality of life for the person with dementia, supporting carers, and helping to avoid a situation reaching a point of crisis which may require intensive input from services. However, currently less than half of people with dementia receive a diagnosis, meaning there is considerable risk that many people are struggling without the support they need.

4.2.2 Why are rates of diagnosis low?

A number of factors were identified that potentially explained the low rates of diagnosis and particularly low rates of early diagnosis. It will be important to address these to increase the number of people with dementia being diagnosed and supported. However, a county council’s evidence highlighted the impact on dementia services of increased numbers of people receiving a diagnosis. This relates to the point made in section 2.2 that the range of dementia services must be considered as a whole. Changes in one part of the system will increase pressure in others.

‘There are significant resource implications for providing a range of interventions for dementia care. For example, if you diagnosis more people we would need more capacity within our already stretched memory clinics, mental health liaison teams and community mental health teams. There are no quick wins in getting this right. Additional investment now would need to be secured for a number of years to see a real change in the care pathway for people with dementia.’

(Anonymous county council, written evidence)

4.2.3 Lack of awareness about dementia and the stigma attached

The lack of public awareness about dementia and the stigma that is attached to the condition was highlighted in the evidence as a barrier to increasing diagnosis rates.

‘We know that (A National Dementia Strategy, Department of Health 2009)

- people currently wait up to three years before reporting symptoms of dementia to their doctor
- 70 per cent of carers report being unaware of symptoms of dementia before diagnosis
- 64 per cent of carers report being in denial about their relative having the illness
- 58 per cent of carers believe the symptoms to be just part of ageing.’

(National Care Association, written evidence)

‘In far too many cases people at home do not understand the importance of recognising symptoms suggestive of early dementia. Even when they do, concerns are dismissed as simple ageing either by the person themselves or by peer group or family. Consequently many people do not disclose their symptoms to a GP.’

(Royal College of Psychiatrists, Faculty of Old Age Psychiatry, written evidence)

‘Early diagnosis can also be delayed by the stigma that surrounds dementia. We would like to see more done to raise people’s understanding of dementia and the potential of people with dementia to maintain a good quality of life and contribute to their communities, often for many years. Destigmatising the condition will encourage early diagnosis and early intervention for best health and cost outcomes. Research involving people with dementia undertaken by the Foundation for the Alzheimer’s Society found that the experience of people with dementia was not adequately portrayed to the wider public, adding to ignorance of the condition and the stigma that surrounds it. (Alzheimer’s society, Dementia: Out of the shadows, 2008).’

(Mental Health Foundation, written evidence)

4.2.4 GP response to signs of dementia

The GP will often be the first point of call for someone concerned about their memory or other symptoms that may indicate the emergence of dementia.

Although the responsibility for diagnosis currently lies with secondary care, the GP is responsible for referring people with suspected dementia to specialist services.

There was considerable discussion during the inquiry's oral evidence sessions about the reasons for GPs' reluctance to refer people. There is some evidence that increasing numbers of GPs consider early diagnosis to be beneficial and are more confident in their ability to recognise dementia, but as Helena McKeown, GP and chair of the British Medical Association committee on community care, noted, this is not universal. GPs are very anxious not to get the diagnosis wrong because dementia is such a serious and much-feared condition. Dr McKeown said 'GPs, most of us, we're quite caring really, we don't want to get this wrong, we don't want to tell people this diagnosis and some people, sadly, do not have the skills to do it.'

There is also a perception among GPs that services to support people post-diagnosis are inadequate, thus deterring them from telling patients that they have dementia.

'I think there is still a reluctance among primary care doctors to attach the horrible label, they might see it, of dementia to what might look like quite clear early symptoms. I think they often feel they're being kind, but they're probably not being helpful in those circumstances.'

(Professor Martin Knapp, Institute of Psychiatry,
King's College, oral evidence)

'GPs are concerned about their skills in making a diagnosis and reluctant to refer to specialist services due to concerns about therapeutic nihilism, medicalising what GPs see as a 'natural consequence' of ageing, concerns that specialist services may not provide any input or that they may be overwhelmed. Many GPs consider dementia to be rare yet demographics would suggest that the number of people with dementia or the number of pregnant women in any practice is very similar.'

(Royal College of Psychiatrists, Faculty of Old Age Psychiatry,
written evidence)

'I took this survey [Mapping the dementia gap, which highlighted differing rates of diagnosis around the UK] to the representatives of the Dorset GPs, the Dorset Local Medical Committee, to ask them their views as to why they are so 'bad' at diagnosing dementia... they talked about, "maybe we just have a much older population". And then I talked to the community psychiatric nursing teams near Salisbury and where I work in Dorset and they said, "Well, it's about resource". A lot of doctors will tell you it's about resources. They don't do the diagnosing because they don't feel the resource is there to look after the individuals.'

(Dr Helena McKeown, BMA, oral evidence)

4.2.5 Training

Witnesses discussed potential ways of increasing rates of diagnosis. Training GPs was seen as important. Consultant Psychiatrist in Memory Services, NHS Isle of Wight, Dr Daniel Harwood, pointed out that it was important to consider how this was done, as reaching GPs with training initiatives can be difficult. It is important to consider what strategies would work best given local circumstances. Personal approaches from specialist dementia services were suggested as a potentially effective method.

However, in addition to training GPs, witnesses argued that other staff members working with people with dementia should be trained to be able to recognise signs of dementia and refer appropriately. The NICE clinical dementia guideline also makes this point.

‘And my colleague, the Chairman of the Royal College of General Practitioners, Dr Gerada, will tell you that they are lobbying for an extension of GP training, a bit like our nursing colleagues, from three years to five years or maybe four, because the place to learn about dementia in the community is not an acute hospital setting as a doctor, but to learn about it in the community, in the care homes, in people’s flats and bungalows and homes from an experienced GP.’

(Dr Helena McKeown, BMA, oral evidence)

‘So I would just advocate very pragmatic training and I just think it’s – we live in difficult times. We’re not going to have hours and hours to do this, so it’s about people in specialist teams going in there for half an hour to a practice meeting with GPs, circulating information, keeping the pressure up and doing it in dribs and drabs.’

(Dr Daniel Harwood, NHS Isle of Wight, oral evidence)

‘Better GP awareness and training is crucial, but so also is a higher level of awareness and training among other staff who are in contact with older populations, such as housing staff and day centre staff, who should be able to detect early signs of dementia and signpost people and families to appropriate support.’

(Mental Health Foundation, written evidence)

4.2.6 GPs as commissioners

There was discussion about the likely changes to commissioning arrangements in England that will give GPs much greater responsibility. There was some concern that the lack of knowledge about dementia amongst some GPs did not bode well for improved commissioning of dementia services. Dr Daniel Harwood argued that the

responsibility lay with dementia specialists to ensure GP commissioners were well informed.

‘It’s up to us, isn’t it, and the provider arms to start discussing with our GP commissioners now and start negotiating now and putting our views across. We can’t just sit back and then complain. We’ve got to take an active role and it’s not just about the providers, it’s about voluntary groups, charitable sector, patient groups, service user groups actually getting on and making contact with the GP consortia and putting their views across, because commissioners need to be listening to a wide range of people, particularly the people who use the services.’

(Dr Daniel Harwood, NHS Isle of Wight, oral evidence)

Conclusion

There are a number of reasons behind the low rates of diagnosis, including the low levels of public awareness and understanding of dementia. The confidence and skill of some general practitioners in recognising dementia continues to be inadequate. Increasing the length of GP training so that it is equivalent to other specialisms would allow for improved coverage of dementia within the GP curriculum. But local areas should also consider how best to develop ongoing training, for example brief, targeted sessions run by specialist dementia services at GP practices. This type of intervention may also support GPs as they take on new commissioning responsibilities.

4.2.7 Diagnosis must be accompanied by comprehensive early intervention

A clear theme that emerged from the evidence was that diagnosis had to be accompanied by a package of follow-up support. The previous experience of some people with dementia has been abandonment following diagnosis until their needs become complex.

As Bupa explained, providing a comprehensive package of support ‘almost certainly result[s] in the person with dementia and those who care for them feeling better supported and more self-sufficient, preventing unnecessary admissions to hospitals and care homes’ (Bupa, written evidence).

‘Really importantly is picking up, following that assessment and following a diagnosis, if a diagnosis is made, with what we call post-diagnostic counselling. So it’s a series of support sessions delivered by a community nurse or a care manager to the carer and followed then,

perhaps, by going into a community day service or accessing helplines or accessing voluntary groups. So it's not diagnosis and then go, which was the old memory clinic model. It's about a whole assessment and then a treatment service being joined up and that's what the memory services I think should be doing. It's much, much more cost-effective and cheaper and time effective to do that rather than just spend your time running around spending hours dealing with complex crises that should have been avoided, and that's the message we need to get across to GPs.'

(Dr Daniel Harwood, NHS Isle of Wight, oral evidence)

A number of witnesses referred to Professor Sube Banerjee's paper, written as an appendix to the National Dementia Strategy for England, which made that case that early intervention is cost-effective because it delays the move into residential care. This package consists of a national network of memory services, support for existing community mental health teams for older people and the enhancement of social services for older people with mental health problems. The cost of this would be an estimated £220 million per year. Professor Banerjee's report predicted a reduction in residential care by the fourth year. It found that a reduction in the use of residential care of 10 per cent would result in annual savings for £120 million in health and social care expenditure and £125 million in private expenditure. The net present value (NPV) over 10 years would be around (minus) £950 million. However, once a modest improvement in quality of life was factored in the NPV would be positive.

4.2.8 Crisis support

In addition to early and ongoing support to help people manage symptoms and avoid crises, a number of witnesses highlighted how services provided at times of crises or strain can help people to stay at home and avoid hospital admission.

CASE STUDY

Flexible enhanced domiciliary care for people with dementia – Waveney, Suffolk

In Waveney Suffolk, the county council and the local PCT commissions a flexible domiciliary care service for people with dementia at times of crisis. This short-term service aims to give an opportunity to stabilise situations, and allow for assessment as to people's ongoing needs.

The service is provided by a domiciliary care agency that recruited staff to work with referrals to it from the older people's mental health social work team. The social care staff have received dementia specific training and benefited from the experience, support, mentoring and supervision of a mental health nurse

line-managing staff and assessing the clients. They also enjoy providing enhanced care to the person with dementia.

The service was established to relieve budgetary pressures on the costly residential care budget. This has been achieved, along with a reduction in hospital admissions. In 18 months it worked with 110 people and:

- supported a number of people to maintain their independence, before returning them to mainstream domiciliary care services
- avoided 46 hospital admissions
- avoided 16 placements into residential care
- avoided at least 25 breakdowns in family care arrangements.

Outcomes from the service are continually monitored and have demonstrated the links between effective support in the community and reductions in hospital admissions.

Funding of the service within the Waveney locality is secure, however, the county council is currently working on a business case for it to be available across the county.

Further information

Read a full description of the project in Department of Health (2011) Living well with dementia: a National Dementia Strategy – good practice compendium http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

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Conclusion

The process of receiving a diagnosis is a means to an end, not an end in itself. It is a first step to getting a comprehensive package of support in place. It is this package, tailored to the individual's needs and circumstances, which will help people to maintain their quality of life and cope with the symptoms of dementia. There are also number of case studies of services which provide support at times of crises which have helped to avoid hospital admission and breakdown in family support.

4.2.9 Pharmacological and non-pharmacological therapies

In terms of specific therapies, a number of witnesses highlighted the new NICE guidance on the drug treatments for Alzheimer's disease. These have been found to be cost-effective and clinicians should consider one of the three anticholinesterase drug treatments for people newly diagnosed with Alzheimer's disease. Ebixa should be considered as a treatment for people with severe Alzheimer's, or moderately severe Alzheimer's if the anticholinesterase treatments are not suitable.

In addition, psychological therapies such as cognitive stimulation therapy were highlighted as useful and cost-effective treatments. The literature review concluded that there was a small but fairly positive body of evidence regarding the cost-effectiveness of cognitive stimulation therapy (CST):

'If we were to see similar investment in some of the alternative psychological therapies as we've seen in adult mental health that would be a really good thing for dementia. So including very basic things that people can do through to CST [cognitive stimulation therapy] and more structured interventions.' (Rachel Thompson, Dementia Project Lead, Royal College of Nursing, oral evidence)

'There's a thing called cognitive stimulation therapy, which has been around now for a few years. It seems to work quite well for people with mild to moderate dementia. It's delivered in groups in day centres or care homes. It looks broadly promising in terms of outcomes and looks broadly promising in terms of cost-effectiveness. It's not yet been tested as delivered to individuals, but in group settings it works quite well.'

(Professor Martin Knapp, Institute of Psychiatry,
King's College, oral evidence)

However, there is evidence that psychological therapies, such as cognitive stimulation therapy, are not widely available, despite evidence of their benefit. As discussed in 2.4.3, Professor Martin Knapp cited reluctance to take up evidence-based interventions as a barrier to improving the overall cost-effectiveness of dementia services:

'And cognitive stimulation therapy, I had an email from somebody this morning who had done a freedom of information request and found that 10 per cent of PCTs and mental health trusts commissioned or delivered cognitive stimulation therapy, but evidence has been around for 10 or more years that it works. So even when we've got the evidence we don't seem to be very good as a system in putting it into place.'

(Professor Martin Knapp, Institute of Psychiatry,
King's College, oral evidence)

4.2.10 Physical healthcare

The British Geriatric Society noted that the review and maintenance of individuals' physical health was important to the effective management of people with dementia. Early intervention in physical health problems can prevent deterioration and potentially avoid hospital admission.

'The key to successful management lies in early diagnosis and there should be attention to optimisation of physical health. Comprehensive geriatric review, review of medication and ensuring that health is optimised will ensure that any tendency for accelerated cognitive decline, emergence of behaviours and functional decline will be minimised. This point is very often not considered. Early management of intercurrent illness is also critical to avert decline. These need not represent additional costs.'

(British Geriatric Society, written evidence)

Bupa also pointed out the potential for treating many conditions in the community:

'Some of the most common causes of the admission of people with dementia to hospital may be prevented or can be treated effectively in the community, whether in the family home or in their care home. This is the case for urinary tract infections, falls and hip fractures and will often be the case for stroke and end of life care. A combination of regular and effective GP review, good community care pathways, rapid response teams, effective nursing in care homes and specialist out-patient clinics will deliver more timely and cheaper care as well as greater satisfaction for service users.'

(Bupa, written evidence)

Conclusion

Evidence suggests people with dementia can benefit from both pharmacological and non-pharmacological interventions and NICE (National Institute for Health and Clinical Excellence) recommends both should be offered from the early stages of the illness. In addition, maintaining people's physical health can help to avoid a decline which could precipitate the need for hospital treatment or residential care.

4.3 Services that could improve quality of life and represent value for money

Witnesses discussed a range of specific community services that improved quality of life and also represented a good use of money. The services identified should be accessible to people in the early and also later stages of dementia.

As noted in section 2.3.1, it is vital that services are tailor-made for the individual. Assumptions that ‘one size fits all’ run the risk of wasting resources on services that may make no difference or are detrimental to quality of life. As one carer noted, ‘If services were offered that “suit” people’s needs/wants, services would be availed of and appreciated and subscribed to.’

4.3.1 Support to continue hobbies and interests

Services that enabled people to maintain their interests and hobbies, for example befriending services, were mentioned by a number of carers. They were felt to be helpful in meeting individual needs and supporting quality of life:

‘Being able to do, in some way and with help, things they have always enjoyed doing: eg, my husband has a carer who “learns” violin with him – it’s invaluable for his morale.’

(Carer, written evidence)

‘Sometimes the only offer is to fit in with a service such as a day centre. This was totally inappropriate for my father who wanted to be outside. Any service should be appropriate to the needs of the individual and not that they should fit in with what is available. Be flexible and responsive to the individual person. I was not able to find a service or volunteer who would simply go out with my father on his regular walks, even if we paid for it.’

(Carer, written evidence)

4.3.2 Support for carers

As noted, most of the care provided to people with dementia comes from family carers. Many witnesses noted that supporting carers to carry on caring at home was vital if the cost-effectiveness of dementia services was to be improved.

Unfortunately, the literature review found that evidence on what works is fairly limited. The authors explained that

‘The shortage of high-quality evidence on interventions to support carers may be due in part to methodological limitations in some of the studies

that have been conducted, the definition of respite care and the wide range of interventions, the variety of needs both for people with dementia and their carers, and the range of outcome measures employed across the literature.’ (Literature review, p21)

Respite care is seen by many carers and other witnesses to be essential. It was argued that this must include night respite care. Many people with dementia are active during the night, meaning carers experience significant sleep deprivation.

‘Respite care is very important for the carer and should be available on a regular basis to enable them to wind down and recuperate. (Dementia often leads to not recognising the difference between day and night, putting great strain on the carer) If no breaks were made available the costs to the NHS would escalate as carers broke down and were hospitalised, leaving both in care. The government is right to increase the amount of money for respite as they have done for the coming year as it will save a lot of money in the long term. I should also wish to see more help in the home made available to carers. This would enable them to keep the patient at home for longer once again bringing down costs in the long term. (I had to put my wife into care as I could no longer cope on my own and extra help was not available at that time. All that I had was a care person for 30 mins in the morning to wash and dress her).’

(Carer, written evidence)

‘The BMA believes that providing carers with adequate support would lead to effective cost savings as well as significant improvements in the physical and mental health of people with dementia, thereby leading to a reduction in the number of admissions to permanent care (which is also the single intervention most likely to produce a significant saving). The BMA believes that the poor availability of respite care hastens the move to permanent care, as does social isolation of the carer. Many patients can be managed during the day but day/night disorientation resulting in disrupted sleep for carers can rapidly cause a crisis. The availability of help at night is crucial. It is usually pressure on carers, who are often elderly themselves, which precipitates admission.’ (BMA, written evidence)

4.3.3 Information and education

It was noted that information and education should form part of the package of support for carers, but also for people with dementia.

‘A key problem is that people have to ask for information, rather than it being provided proactively. Most people do not know what they have to ask for. Carers also reported how lack of information at the appropriate time exacerbated problems and led to unnecessary interventions. The example was given of pressure sores. The individual caring for his wife at home was not made aware that pressure sores were a potential risk or of how to reduce that risk or spot the early signs. A pressure sore did develop and took intensive support from district nurses to treat. That could have been avoided if information on pressure sores had been provided in a timely way.’

(Alzheimer’s Society, written evidence)

‘In the person’s own home the main barriers are:

- 1 Lack of diagnosis of dementia and information about the person and his or her cognitive function. Improved diagnosis and a register would improve this.
- 2 Caregivers’ lack of knowledge about dementia and its features. This leads to a culture of “if in doubt call an ambulance”.’

(Ealing and Harrow service provider, written evidence)

Volunteer carers and people with dementia are working in some areas to provide advice and information to people in similar situations. In its written submission ADASS referred to the ‘EDUCATE’ project in Stockport, which is enabling volunteers in the early stage of dementia to help raise awareness and educate others.

One carer described how helpful he had found learning about the Specialised Early Care for Alzheimer’s (SPECAL) approach to caring for people with dementia and recommended that it be taught more widely to people caring for individuals with dementia.

4.3.4 Peer support services

Peer support services can be a useful way of providing information, as well as being an opportunity for relaxation and enjoyment. It was noted that this type of support need not be costly.

‘Social activities with others such as a pub lunch club and memory cafes where they can socialise without feeling demeaned or stared at and which provides a safe environment for them in which the carer too can relax and chat to others in the same situation. Memory cafes are particularly good for this as the person with dementia can mix in and

participate and be listened to by people who understand and have the patience to listen and talk and discuss things with them.'

(Carer, written evidence)

'In Lambeth and Southwark we have been using volunteer ex-carers as peer supporters to provide advice and reassurance to carers which in turn helps enable them to manage to care for the individual with dementia. The peer supporters also provide support when the person with dementia is newly diagnosed and is being helped to make decisions about their wishes with regards to their future care while they have the capacity to do so.'

(Amanda Thompsell, St Thomas' Hospital, written evidence)

Alzheimer's Society explained that peer support groups can allow valuable pieces of information about coping with the symptoms of dementia to be shared. It wrote:

'As noted, many people report difficulties in accessing the information they need to live well with dementia and it is often a case of having to ask, which is impossible if you do not know what you should be asking about. Peer support groups enable information to be shared in an informal way. Examples provided by carers include the best methods of dealing with night time incontinence.'

4.3.5 Telecare and assistive technology

A number of pieces of written evidence referred to the potential for greater provision of assistive technology and telecare to increase the cost-effectiveness of dementia services. Examples of telecare services include GPS systems and medication dispensing tools.

'Exploration of the greater use of telecare. Occupational therapists can act as facilitators of telecare. Evaluations from local telecare interventions reveal savings around emergency hospital and residential care admissions ie £85,837 as a result of saved bed days.'

(College of Occupational Therapists, written evidence)

'Staff costs could be saved with the use of more assistive technology and possibly the service user would benefit from increased privacy and ability to stay at home or self-care for longer periods.'

(National care home provider [anonymous], written evidence)

4.3.6 Good-quality home care

A number of witnesses reported that in some areas that money was being wasted on community services that were of poor quality and therefore not able to effectively meet people's needs. For example, staff may not have a good understanding of dementia:

'Inexperienced care workers who provide "useless" sitting services – that are not stimulating, ie do no meaningful activities etc. These services fail to provide suitable respite for family carers.'

(Carer, written evidence)

Other problems with the provision of home care were highlighted, which detracted from their usefulness.

'Yes – I hear often of the dissatisfaction on receiving home care ie not arriving or arriving very early or very late and are rushed to complete the task required – surly and too many different helpers. Meals delivered for oven and not microwave – ie metal containers and [food] of poor quality.'

(Dementia support worker, written evidence)

The poor time-keeping of home care staff and the frequent changes in personnel were also highlighted as reducing the effectiveness of the service.

'Mental health home treatment teams rarely arriving in the chosen 2-hour slot and so many different members of the team visiting, no continuity, causing anxiety to patient.'

(Carer, written evidence)

The Mental Health Foundation noted a recent research study, which concluded the quality standard of the community support was the key determinant of the cost effectiveness of a service, rather than whether it was a specialist dementia service or a generalist service:

'The APPG will also be aware that the Personal Social Services Research Unit (PSSRU) at the University of Manchester has recently published its Expert Briefing Paper 2 on Community support services for people with dementia: The relative costs and benefits of specialist and generic domiciliary care services... Overall it did not matter in terms of cost or effectiveness whether it was specialist or generalist care model. What mattered more was conforming to good practice or quality standards for dementia care – picking up the point we made earlier about quality of care not necessarily depending on cost or location.'

(Mental Health Foundation, written evidence)

A number of witnesses also raised the quality of day services as an issue. It was noted that a well-run day service could be a very good use of resources that improved quality of life, while poorly run services were very unhelpful. It was argued that it need not cost any more to run a service well.

‘Day services can be appalling if they’re run badly or they can be brilliant if they’re run well and the secret to running them well is having structured meaningful activity and in our day services we use a form of cognitive stimulation therapy, but it doesn’t stop there. The providers of the service also provide carer support and information for people attending and provide monitoring for people on anti-dementia drugs, reducing the need for outpatient clinic appointments and CPN visits and so on. So if they’re run properly, they can be a very cost-effective way of delivering a service, but they have to be run effectively.’

(Dr Daniel Harwood, NHS Isle of Wight: oral evidence)

‘My mother has for years been enabled to do this [live life to the full] via a wonderful day centre, Bay Tree Resource Centre in Moor Allerton, Leeds, where the joy meets you at the door and embraces you. I’ve seen some dreadful, miserable day centres and yet it’s clearly quite possible to run them well and with emphasis on what people CAN do, rather than what they can no longer do. We should be sharing best practice and ensuring that resources are used to fund joyous day care, not simply a minding service (crucial though it is to offer carers essential respite). Doing it well costs no more than doing it badly!’

(Carer, written evidence)

Conclusion

There are a number of specific types of services that have the potential to improve quality of life and the overall cost-effectiveness of dementia services. These include day centres and services that enable people to carry on with interests and hobbies. Support that enables carers to carry on caring for people at home is also essential. This should include day and night respite care, as well as information and education.

Peer support for both people with dementia and carers was also valued and recommended. The quality of the services provided is of paramount importance. Individuals reported receiving poor-quality services that were wasteful and of no benefit, sometimes with potentially harmful results.

4.3.7 Key worker

Several pieces of written evidence noted how the provision of a key worker would be an effective use of resources. It was perceived that one individual co-ordinating care would improve the organisation of a care package, enable problems to be spotted and dealt with early on and also reduce the duplication of assessments. The literature review also found that evidence on case or care management is quite encouraging, particularly with suggestions of longer-term cost-effectiveness.

‘The duplication of assessments could be reduced. Accessibility of information and support could be achieved by having Admiral Nurses. Greater co-ordination between services and clearer paths could save money.’

(Carer, written evidence)

‘Provision of a key worker. At the moment there is little cohesion between services. It all seems very random.’

(Carer, written evidence)

The particular usefulness of key workers for those that live alone was highlighted.

‘A person who lives alone with dementia could deteriorate in many ways and become seriously neglected or ill. No "key worker" has been assigned to our friend to carry out regular checks on her health and well-being. Such a person could help to prevent serious illness or accident and keep people out of hospital. "A stitch in time saves nine" applies here; keeping people with dementia well at home is an important cost saving measure.’

(Carer, written evidence)

‘But I would agree with the co-ordination and I think it’s a message that we hear constantly from people with dementia and families saying ... you trust them and they are the people who can almost protect you and guide you and help make sure that you get the right care and the right access. Because when you’re struggling with an illness or struggling with caring, actually it’s difficult just to get through the daily thing, never mind having to work out what the system offers. So I think co-ordination is crucial.’

(Rachel Thompson, Dementia Project Lead,
Royal College of Nursing, oral evidence)

The issue of which professional would be best placed to act as a key worker was discussed at the oral evidence sessions. The view tended to be that this should depend on individual circumstances.

‘But I think it may depend on what the predominant stability of the condition is or whatever, because I can see a social worker acting as a co-ordinator if the primary need is for social care support, support for the carer and so on, and episodic need for health care input. But it might be that the reverse is true, in which case I’m not sure a social worker would be the right co-ordinator. So it might be more about working out what the role is, what the functions of the co-ordinator role might be and then I think it will probably vary from individual to individual as to who is best placed to take up that particular role.’

(David Walden, SCIE, oral evidence)

‘It might be that at different stages of the journey there might be a different person who’s better around the co-ordination. I think nurses certainly have a good part to play and I’m sure economics and costs will come into whoever that co-ordinating role is.’

(Rachel Thompson, Dementia Project Lead,
Royal College of Nursing, oral evidence)

‘Without being clever, I think very much it depends on what stage of the journey you are. I would ask the patient or the carer who they would see as their one individual. I think the idea of being that individual with the illness or being their carer and having one person to look to is a very, very good idea. If they have a usual doctor, if they have a GP who really is their GP who they have continuity with, that’s quite well placed in parts of the illness, without a doubt.’

(Dr Helena McKeown, BMA, oral evidence)

CASE STUDY

Care navigation – Barnsley

Barnsley Dementia Service have piloted a ‘care navigators’ role to guide the person and their carer through their journey with dementia. The role of the care navigator is to provide a central point of contact for the person and their carer in accessing health and social care services and third sector organisations. The underpinning philosophy of the care navigators is to empower individuals and provide choice to sustain independence and optimum levels of functioning.

Evaluations showed:

- reduced isolation and increased confidence for the person with dementia
- increased carer support

- improved access to information
- half of people reduced their contact with their GP by 50 per cent
- a 20 per cent reduction in admissions to dementia assessment ward from the two GP practices
- earlier discharge from the dementia assessment ward with care navigator involvement
- reduced length of time on memory staff caseload.

Following the pilot, Barnsley Dementia Service has undergone a service redesign in line with the National Dementia Strategy targets. The role of the dementia care navigator has been retained and is currently being tested in both the diagnostic and the enduring care pathways. Early feedback from people with dementia and their carers is that it is an invaluable service giving timely advice, support and encouragement to live well with dementia.

Further information

Read a full description of the project in Department of Health (2011) Living well with dementia: a National Dementia Strategy – good practice compendium http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123476

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Conclusion

The ability of a 'key worker' system to improve the quality and cost-effectiveness of care was supported by research findings, as well as the views of professionals and people living with dementia. The co-ordination of the disparate parts of the dementia care system would be welcomed by carers and people with dementia, who find the current system confusing and difficult to navigate. The care management role could be taken on by a range of professionals, depending on the individual circumstances of the person with dementia.

4.3.8 Personal budgets

There were mixed views on whether the move to increase personal budgets would significantly improve cost-effectiveness of dementia services and the quality of life of people with dementia. The current evidence is mixed and there appear to be different outcomes for particular groups of people.

‘I think that individual budgets, direct payments, personal budgets I think are one of the most promising developments we’ve seen in this area. There’s a long way to go and, of course, many people who get those budgets are not receiving support from every pocket, but I think if we give that freedom to individuals to choose what services they want those individuals do not have a bit of their bank account called ‘health’, another bit of their bank account called ‘social care’ and we just need to break that down. Now, I know it’s not easy and we haven’t got the solution yet, but moving in that direction I think is the most promising from my point of view.’

(Professor Martin Knapp, Institute of Psychiatry,
King’s College, oral evidence)

‘I think I would be a bit more concerned about how effectively that would work for people with dementia and who might not have as much say in what services they get. And also, I think it’s been looked at from end of life care and the view was that it wasn’t really appropriate for end of life care. So I think there’s not enough yet known. Where it’s worked it’s tended to work for the relatively fit and younger people.’

(Karen Taylor, formerly Director of Health Value for
Money at National Audit Office, oral evidence)

‘We [SCIE] published a report recently on personalisation and efficiency and whether personalisation as such is a way of saving money. And the conclusion is that there’s not enough evidence to date to be able to claim that, but there are good examples of where, for example, personal budgets for people with dementia, administered often by their family carer, can make savings because they can keep them at home for longer rather than, as I say, having an admission into a care home. There’s a case study in that report about one gentleman who, because he had a personal budget, there was a saving overall to the system of £12,500 a year compared to the alternative of residential accommodation. So that’s just one example.’

(David Walden, SCIE, oral evidence)

There is evidence of a very low uptake of personal budgets among people with dementia, as the Mental Health Foundation explained:

‘There are a number of reasons for this including low levels of awareness and understanding among people with dementia and their families, as well as social care staff working with them, social services systems not being well designed to support people with dementia wanting personal budgets, and there being a lack of variety in the services available to purchase with a personal budget.’

(Mental Health Foundation, written evidence)

Conclusion

Although personal budgets have been found to be very helpful for some individuals, there is little evidence that they would help everyone at the moment. Their use is currently not widespread. There are a number of reasons for this, including a lack of services for people to purchase. The market will need to be developed if personal budgets are to be most effective, so that choice is available. However, it is unlikely that increased use of personal budgets will be sufficient to stimulate the market; other measures are required.

5 Care homes

5.1 Introduction

At least two-thirds of care home residents have dementia.³⁴ While supporting people to live in their own homes has been a focus for policy in recent years, it is likely that many people with dementia will eventually need to move to residential care as their symptoms progress. One witness observed that, ‘for some time we have recognised that the future demand for admissions to care homes will come primarily from those living with dementia.’ (Nightingale House Care Home, written evidence). It is therefore vital that this sector is organised and supported so that it can help people with dementia to achieve a good quality of life, while also adding to the cost-effectiveness of the dementia care system overall.

This chapter considers how the quality of life of people with dementia can be promoted within care homes and what measures are required to attain this. It also looks at how care homes can play their part in promoting the cost-effectiveness of the dementia care system, particularly by reducing the need for more expensive types of care.

5.2 Improving quality of life within care homes

A number of reports have shown that, while some care homes are excellent and much valued by residents and relatives for the high standard of care they provide, there are still too many that are not good enough.^{35,36} In addition, there are many reports, training guides and other publications that support care homes to improve the care they provide. A number of witnesses discussed some of the problems within homes and also what is required to ensure homes support good outcomes for people with dementia. Recurring themes were the provision of enjoyable activities and also a suitable physical environment.

‘Care homes for people with dementia should be purpose-built, with space and light and the provision of safe areas to wander and be outside. Quiet areas for peace and activity areas that relate to the person and their life memories. This could include day-to-day activities that men and women would have done with their families and at home.

34 Alzheimer’s Society, Dementia UK, 2007

35 Alzheimer’s Society, Home from Home, 2007

36 Commission for Social Care Inspection, See me, not just the dementia, 2008

Staff would need to be trained to allow a certain amount of risk, within a carefully agreed care plan for individuals.’

(Age UK, written evidence)

‘Once a person with dementia is admitted to a residential facility, the means for family to come and go at will at whatever time of the day or night, to join in meals and/or other activities, to take the person out – in other words, to treat the care unit as a true home – is very positive. Time and efforts made by the (well-trained and experienced) staff to get to know and ‘socialise’ with their charges made, in my view, a significant difference to the quality of life experienced by my father and others. The home where my father lived his final years was sufficiently relaxed to permit his nightly tot of whisky, one example of a number of small but helpful elements for him in retaining something of his personal choices and routines.’

(Carer, written evidence)

Nightingale House Care Home described the new purpose-built dementia facility that it is building. It was designed using specialist architects and Nightingale is also working with the Dementia Centre at Bradford University to ensure the philosophy of care changed from task-orientated to person-centred care. Leon Smith, Chief Executive, Nightingale House Care Home explained, ‘It needn’t be more expensive. It’s just a question of staff being trained that every single simple interaction with a resident is an activity and even taking somebody from their chair to the loo can be a quality moment. It needn’t be more expensive; it’s just different.’

5.2.1 Staff training and support

The importance of training and supporting staff to provide good-quality, cost-effective care is an overarching issue and is discussed in chapter 2. The evidence made clear that the skills and attitudes of staff were of paramount importance in promoting the quality of life of care home residents. In light of this, many witnesses argued that staff must be better trained, supported and valued.

The Royal College of Psychiatrists also pointed out that, in addition to training and education, more work needs to be done on understanding and addressing high stress levels experienced by care home staff:

‘In care homes we find some of the most vulnerable people in society and yet staff involved in their management are readily demonised by the media and the general public. In many cases staff work in conditions which would not be accepted in the NHS. Turnover is rapid and training opportunities limited. The Alzheimer Society report, Home from home, and the Mental Welfare Commission for Scotland’s report, Remember

I'm Still Me, highlight many of the problems associated with the alienation of care homes within society and the viewpoint that residents have become a 'forgotten tribe'. Antipsychotic use is higher in care homes than in hospitals or in the community ... If we are to improve quality of life in care homes the answer lies not simply in "training and education", but in gaining a clearer understanding of staff stress and burden and a clearer understanding of how interpersonal interaction influences behaviour in a long-term enclosed environment.'

(Royal College of Psychiatrists,
Faculty of Old Age Psychiatry, written evidence)

The college argues that by reducing the number of care homes and 'tackling societal over-dependency on care homes as a "solution"', we could increase the staff ratio in the care homes, thus improving care without increasing cost.

Conclusion

It is vital that care homes are able to provide a good quality of life for people with dementia, given that most care home residents will have some form of dementia. Well trained and supported staff are essential to the provision of good-quality care. The support for staff must go beyond training sessions and should respond to the stress experienced by care home staff.

5.3 Care homes as part of the community

Evidence received discussed work to encourage care homes to become a more integral part of the community and of the local dementia care system. This was considered to be an effective way of improving quality of life of residents. Barchester Healthcare explained that:

'Homes for people living with dementia should also move to a greater role as a part of local communities and as community resources. Greater community involvement would improve the quality of life for residents through better opportunities for social interactions. Providing a community resource from an existent residential home saves money by working with marginal costs to provide services for people in need of help. Examples current within Barchester would include use of homes for dementia cafés and for partnership working with Admiral Nurses. However, the scope of care home involvement could be broadened to include provision of memory clinics, 24-hour advice and emergency support, advocacy,'

(Barchester Healthcare, written evidence)

The potential for care homes to provide a range of services beyond residential care was highlighted by witnesses:

‘Nightingale currently has a satellite audiology clinic operating on its own premises from the team based at St George’s Hospital, [London]. It may well be that there are other such areas which are dementia-related, which could take place in the community and/or in a care home setting, thereby reducing the number of people attending out-patient clinics and saving unnecessary cost of transport.’

(Nightingale House Care Home, written evidence)

The National Care Association provided the example of Quarry Mount, a residential home in Stroud, Gloucestershire. The home is developing

‘...an outreach service, which offers members of the older community the change to have a meal at the care home with the residents and/or make use of the bathing facilities. The person will have the option of joining in with any of the activities while they are visiting the home. This is an excellent development opportunity, which once again takes the residential home into the community and brings the community into the home, thus providing cost-effective care for people with dementia who are living at home or being cared for by relatives.’ (National Care Association, written evidence)

This service has not yet been evaluated as it is still in its infancy.

A number of respondents also discussed the provision of short-term care in care homes. This could include night respite to give carers a much-needed break, or as intermediate care to avoid hospital admission or reduce length of stay.

‘The BMA would support the use of nursing home respite places for interim placement of those in hospital who cannot go home, as an interim move while substantive placement is achieved. In this instance, dementia patients should be allowed to queue jump to nursing homes because extending their stay in acute hospitals would simply cause them harm and is very expensive.’

(BMA, written evidence)

Bupa highlighted the potential cost savings of using care home beds to expedite the discharge from hospital of people with dementia.

‘An example of expediting the discharge of people with dementia from hospital is provided by a specialist reablement service in a Bupa care

home in Stoke-on-Trent. Beds were commissioned, originally by social services and the PCT jointly, and detailed processes have been developed both to expedite discharge from hospital and then from the care home. Specialist staff from the home visit the hospital daily to assess the suitability of referred patients for any available beds, ensure continuity of medication and treatment and make immediate contact with the family, GP and other professionals involved. A plan and target date for discharge from the home are created within the first week after admission and a multi-disciplinary team (including a social worker, physiotherapist and occupational therapist) work closely with the care staff to deliver this.'

(Bupa, written evidence)

Bupa described the cost savings achieved by using care home beds rather than hospital beds. 'This year's NHS tariffs for each additional bed day in hospital vary from £200-280, depending on the specific condition being treated, so are likely to average a minimum of £1,500 per patient week, compared with the care home's current contract rate of £718 per week.'

Conclusion

It is important that people living in care homes are not isolated from the rest of the community. Opportunities to get involved in the wider community and inviting non-residents into the home could enable residents to have a wider social network and maintain enjoyable activities. Providing services within the care home to non-residents with dementia could represent an effective use of existing resources and encourage the embedding of the care home into the wider dementia health and care system.

5.4 Joint working between care homes and other dementia services

A key theme of the evidence was improving quality of care and also value for money by increasing the amount of joint working between care homes and other sectors within the dementia care system.

A number of witnesses discussed the value of outreach teams from local specialist dementia services working with care homes. Not only was this seen as a way of improving the quality of dementia care provided to care home residents, but it could also reduce the risk of people with dementia being admitted to hospital because, for example, they were experiencing behavioural symptoms that the home was not equipped to avoid or respond to appropriately. Supporting care homes to better

prevent and respond to behavioural symptoms could also reduce the inappropriate use of harmful antipsychotics.

Witnesses cited evidence that care home liaison services could reduce hospital admissions and were cost-effective:

‘A specialist liaison team was established in Doncaster in 2006 to provide mental health support to local care homes. After the first year, admissions from care homes to hospital had been reduced by 75 per cent. The team has also been highly active in delivering training to care home staff and co-ordinating the work of care homes, mental health services and social services.’

(King’s Fund, written evidence)

Oakbridge Retirement Village in Lancashire described its residential/housing based care environment for adults experiencing dementia who have had a history of exhibiting challenging behaviour or require section 117 aftercare following a section under the Mental Health Act. With the close support of local GPs and community mental health teams the service is able to provide care for people with dementia who might otherwise find themselves being readmitted to hospital or moved between several homes.

CASE STUDIES

Dementia outreach service for care homes – Isle of Wight PCT

Isle of Wight PCT has reduced the number of inpatient dementia units and used the money released to provide a Dementia Outreach Service (DOS), staffed by nurses, to support people with dementia with behavioural and psychological symptoms in care homes.

The DOS can be accessed by staff working in care homes, and they can:

- obtain telephone advice
- request an assessment and/or follow up appointment
- involve another member of the memory service for advice or support, such as an occupational therapist, community psychiatric nurse or old age psychiatrist.

Isle of Wight PCT believes the DOS offers a cost-effective approach to reducing admission and preventing readmission to hospital; reducing the inappropriate prescription of antipsychotic drugs; and reducing the incidence of depression among people with dementia. The PCT plans to reduce inpatient beds even

further over the next year, which will free more resources to provide more outreach support.

Isle of Wight PCT argues that the key to better care in care homes is improving the attitude and the skills of the care home staff. To this end, the DOS provides an informal education and training programme for staff. This usually involves a member of care home staff approaching the DOS if they are concerned about an individual displaying intense behavioural and psychological symptoms of dementia and the DOS will then work with them to write up an appropriate care plan. The ethos is very much based on empowering staff and helping them to consider possible solutions in response to the symptoms in order to adopt similar strategies for other people. The DOS is at a very early stage in its development and, therefore, there is a lack of data on outcomes.

24-hour support line for care home staff – Isle of Wight PCT

Isle of Wight PCT runs a 24-hour helpline for residential care home staff, which provides staff with advice on how to manage a person's behavioural symptoms without calling the GP. This service is intended to lead to a reduction in the inappropriate prescription of antipsychotic drugs for people with dementia and the use of alternative treatment strategies.

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Conclusion

Care homes are a core part of the dementia care system and they must be given the necessary support to provide high-quality dementia care. Care homes can benefit significantly from the support and advice of older people's mental health teams, particularly in relation to responding to behavioural symptoms. A well supported home could mean reduced use of antipsychotics and avoidance of unnecessary hospital admissions, thus savings costs and improving quality of life.

There are also examples of care homes that work in partnership with local health services to provide much needed specialist support for people with high-level needs, who may otherwise experience multiple moves and hospital admissions.

5.5 Supporting physical healthcare

The point was made that support to enable residents' physical healthcare to be managed better within the care home would also represent a sensible use of

resources. Preventing deterioration in physical health would again support residents' quality of life, but also potentially avoid hospital admission. Support from GPs was perceived to be important. The British Geriatric Society also discussed the potential for geriatricians to work more closely with nursing homes, to improve the physical healthcare they receive within the home and thus help to avert hospital admission.

'Having regular input into care homes by GPs who have an interest in this particular area we have found increases the confidence of staff to manage medical issues.'

(Dr Amanda Thompsell, St Thomas' Hospital, written evidence)

'Support for care homes and general practitioners either through improved interface between hospital and care home and/or community geriatricians. With the emergence of community geriatric medicine as hospital beds close and management moves more and more to the community, a key to success will be the utilisation of the skills of geriatricians appropriately in the community and it could be that an increasing role in nursing homes might be the best value for money. Often admission to hospital occurs from care homes because of [a] relative lack of GP input. These are very frail old people with dementia where input at the right time from a geriatrician in terms of decisions about intervention for physical illness can be critical. This could avert significant numbers of hospital admissions.'

(British Geriatric Society, written evidence)

Alzheimer's Society referred to the use of elderly care physicians within care homes in Holland. Their support with the healthcare of residents contributes to the very low rates of admission from care homes to hospitals in Holland.

It was emphasised that while initial investment may be required to instigate new ways of working, the potential for geriatricians working within care homes to reduce hospital admission would result in substantial savings.

Conclusion

Support to enable care homes to provide physical healthcare can help to avoid the financial cost of hospital admission, as well as the cost to health and well-being. Initial investment may be required, in addition to a willingness to try new ways of working – for example geriatricians working closely with care homes. However, the benefits of reduced hospital admission could be substantial. Residents' well-being will also be better maintained if their physical health and comfort is well supported.

5.6 Providing palliative care in care homes

The potential for care homes to provide better palliative care, through support from specialist palliative care services was also highlighted. The National Council for Palliative Care stated that 59 per cent of people with dementia die in care homes. It pointed out, 'Investment in end of life training for care home staff will not only improve the quality of care a person receives but also help equip staff to avoid emergency hospital admissions.'

A range of witnesses described how they had improved the care homes' ability to provide palliative care:

'There is evidence from the St. Christopher's project in Croydon that palliative care input can reduce inappropriate hospital admissions and improve quality of end of life care for people with dementia and their families. We have developed the role of nurse facilitator in end of life care for people with dementia. This role is best described using the liaison mental health model. The liaison approach is proactive and not limited to direct patient contact. It aims to integrate the assessment and treatment of advanced dementia end of life care into routine practice. This is done by role modelling, facilitation and training to enable care staff to deliver care themselves with support.'

(Dr Amanda Thompsell, St Thomas' Hospital, written evidence)

It was argued that families can have an expectation that a person will be transferred to hospital if their condition seriously deteriorates, so supporting the family to understand when this is appropriate and how it can safely be avoided, will also be important.

CASE STUDY

Dementia specialist care home providing palliative care – Bupa

A Bupa dementia specialist care home in Cambridgeshire has won two national awards for its work in providing palliative care. This is overseen by the Peterborough Group for Palliative Care in Dementia, a multidisciplinary group drawn from primary and secondary care and the care home sector.

Bupa identifies two key elements making the service successful:

- early and close family involvement and support
- a highly developed partnership with local GPs, with agreed and detailed protocols for every stage of the pathway.

The Cambridgeshire care home introduced an adapted version of the Liverpool Care Pathway – an integrated care pathway, which provides guidelines for looking after people when they are dying. In Cambridge this adapted pathway is in use, supported by a specialist GP who holds regular reviews and offer guidance on palliative care to care home staff.

Regular reviews happen every month at a significant event meeting. At this meeting, all developments over the previous month are reviewed for a person nearing the end of their life and, if possible, pre-emptive advance care interventions are introduced into the care plan. Any acute issues are reviewed weekly, often turning to daily at the end of life. The specialist GP will attend at all times towards the end of life to review a range of issues, for example medicines, prescriptions, medical interventions, family support and resident's wishes about end of life. At least once yearly a 'gold standards framework prognostic indicator' is completed to capture all of the above information as well as documenting trends in weight and a resident's ability to perform activities of daily living.

Bupa has found that by assigning a named GP to a care home and ensuring the GP has responsibility for the health care of its residents has the potential to enable better medical care and improve relationships with care home staff. In turn care home staff are trained in end of life care for people living with dementia.

Families predominantly express a preference for hospital admission over remaining in a care home at the final stage of a person's life. Bupa argues this service provides continuity within a dignified and homely environment, for the resident and for their family.

End of life care in hospitals can be very costly and often not the most appropriate setting for the person with dementia. Bupa's analysis shows the cost of this service in a care home may be as little as 10 per cent of the tariff in a hospital's critical care unit and would rarely, if ever, exceed 20 per cent of that rate.

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Conclusion

A significant proportion of people with dementia will be living in a care home at the end of their lives. Support for care homes to provide good palliative care can avoid the need to move people to hospitals in their last days. Outreach support

teams can enable this to happen. Many people would choose to die in the care home that has become their home, rather than be moved to a hospital, and families may also prefer this. Directing money to facilitate this, rather than to fund hospital admissions, appears to be a more effective use of resources and could also be cost-saving.

Appendix 1: Further policy context

At the time of publication there are several initiatives and developments in the UIK relevant to delivery of dementia care services and the quality of care for people with dementia.

National Dementia Declaration for England

In October 2010 an alliance of organisations published commitments to deliver better quality of life for people with dementia and their carers. This Dementia Action Alliance now exists as a coalition of over 50 organisations, including the APPG on Dementia. Each organisation in the alliance has signed up to the National Dementia Declaration, setting out its commitment to radically change quality of life for people with dementia by 2014 and has published an action plan describing its role and commitments.

Commission on funding of care and support in England

The Commission on the Funding of Care and Support has been set up as an independent body to advise the government on a range of funding options for social care in England following the commitment in the coalition government agreement.

Launched in July 2010, the commission is chaired by Andrew Dilnot, with Lord Norman Warner and Dame Jo Williams as fellow commissioners. The commission is building on the body of work that has already been done in this area and is to provide recommendations and advice to government on how to implement the best option of funding by July 2011. The government will consider the report and then decide how to proceed, with an expectation that there will be a White Paper and legislation to follow.

The current system of charging for care in England often hits people with dementia and their families hardest, as they often rely on social care for help with essential daily activities such as eating, using the toilet and bathing. This is because most of this kind of care is provided by care staff from social services, which in England is means-tested and generally not provided free of charge by the NHS. This happens even though people with dementia have a physical disease of the brain, and many people with other medical conditions receive NHS funded care.

The report from the commission will look to offer solutions for England only, but it may have an impact on Wales and Northern Ireland.

The 2011 Health and Social Care Bill for England

The Health and Social Care Bill, introduced to Parliament on 19 January 2011, explains the government's intentions to reform the NHS and gives new responsibilities to local authorities to join-up working between health and social care. Following a public listening exercise between April and May 2011, the government announced substantial changes to the bill. Key proposals in the bill, which reflect these changes, include:

- The creation of clinical commissioning groups, which will commission services on behalf of their local communities. These will be made up of groups of GPs practices but will also involve patients, carers and the public and a range of doctors, nurses and other health and care professionals.
- The creation of the NHS Commissioning Board – the bill will abolish primary care trusts and strategic health authorities and this new board will be responsible for the provision of primary health services and holding commissioning groups to account.
- Local authorities must establish health and well-being boards (HWB), which will have a role in promoting joint commissioning and integrated working between health and social care. HWB will be involved in the developing commissioning plans with clinical commissioning groups.
- The creation of national and local 'healthwatch', which will promote and support patient and public involvement in care and health services.
- There will be duties on the NHS Commissioning Board and clinical commissioning groups to involve patients, carers and the public in commissioning decisions.

The bill provides a range of opportunities to strengthen integration between health and social care, which is important for people with dementia and their carers who are heavy users of both health and care services. It is also significant that clinical commissioning groups, which will involve a range of health and social care professionals, will be responsible for commissioning dementia care services in the future.

Vision for adult social care

In November 2010 the government launched, A vision for adult social care: Capable communities and active citizens. The document sets out how the government wishes to see services delivered for people in England: more personalised, more preventative

and more focused on delivering the best outcomes for those who use them. It also aims to give frontline workers and carers the freedom and responsibility to improve care services and support people in new ways.

The vision for adult social care emphasises that the Spending Review prioritised resources for social care and partnership working with the NHS. It places responsibility with councils working with their local communities and those who already provide care as a carer, family member or neighbour, to make a reality of this vision.

Transparency in outcomes: a framework for quality in adult social care (2011)

The Adult Social Care Outcomes Framework (ASCOF), published for consultation in England in November 2010, aims to promote a broader, more transparent outcomes-based approach to social care in England. The framework is based around four broad domains, which set out the major desired outcomes for social care. Local authorities' performance against these domains will be assessed against a series of indicators or 'measures'. The 2011/12 ASCOF is not an end point, but is still developing.

People with dementia are significant users of social care which makes this framework particularly relevant to them, though it currently includes no measures specific to dementia.

'Big society'

The Government's 'big society' is a radical new vision for the delivery of public services. Schools, hospitals, police forces and welfare providers will be given greater freedom from central control and become more accountable.

Public services are to be run by the private sector, new mutuals, charities and social enterprises with providers rewarded for the outcomes they achieve. This is a huge challenge for those wishing to be involved in the delivery of services.

People with dementia are significant users of public services, which indicates that the development and potential failure or success of this initiative could directly affect families living with dementia.

Wales Assembly Government social services paper: Sustainable social services for Wales: a Framework for action, 2011

This paper was published in February 2011 following, From Vision to action, a report by the Independent Commission on Social Services, published in November 2010.

It sets out the priorities for action for the future of social services and social care in Wales, one of which is creating integrated services. To add momentum to this priority, three areas of work have been prioritised, one of which is frail older people. Within this one of the biggest issues to address has been identified as dementia, and the implementation of the Dementia Vision for Wales.

A programme of policy and legislation will be brought forward to implement these actions. Implementation of the first stage of commitments will be by December 2011.

Appendix 2: Organisations that submitted written evidence

- 1 Association of Directors of Adult Social Services
- 2 Age Concern Essex
- 3 Voluntary provider (anonymous)
- 4 Age UK
- 5 Alzheimer's Society, Bedfordshire and Luton
- 6 Alzheimer's Society, Cambridge
- 7 Alzheimers Society, Carlisle
- 8 Alzheimer's Society, National response
- 9 Arts and Minds
- 10 Barchester Healthcare
- 11 British Geriatrics Society
- 12 British Medical Association
- 13 British Specialist Nutrition Association (BSNA)
- 14 Local authority (anonymous)
- 15 Bupa
- 16 Cheshire East Council
- 17 College of Occupational Therapists
- 18 Counsel and Care
- 19 Care Quality Commission (CQC)
- 20 Cumbria Care Adult and Local Services/ Cumbria County Council
- 21 Department of Health Good Practice Compendium (a)
- 22 Department of Health (b)
- 23 Ealing and Harrow Provider Services
- 24 ECCA
- 25 Elizabeth House & Moorfields Care Homes, Bury
- 26 Great Western Ambulance Service NHS Trust
- 27 Housing 21
- 28 Humphrey Booth Resource Centre

- 29 Independent consultant nurse
- 30 Independent consultant
- 31 Independent paid live-in carer (anonymous)
- 32 Isle of Wight PCT
- 33 James Paget University Hospital
- 34 Liverpool PCT
- 35 Manchester Mental Health & Social Care Trust
- 36 Mental Health Foundation
- 37 MHA Care Group
- 38 National Care Association
- 39 National Care Forum
- 40 National Council Palliative Care
- 41 National Institute for Health and Clinical Excellence
- 42 NHS Eastern and Coastal Kent
- 43 NHS Great Yarmouth and Waveney
- 44 Primary care trust (anonymous)
- 45 NHS North Somerset
- 46 Nightingale House Care Home
- 47 County council (anonymous)
- 48 Local authority and pct (anonymous)
- 49 Oakbridge Retirement Villages
- 50 Old Age Faculty of the Royal College of Psychiatrists
- 51 Oxford and Bucks Mental Health Trust, Dept. of Spiritual and Pastoral Care.
- 52 Royal College of Nursing (RCN)
- 53 Redbridge Respite Care Association
- 54 Social Care Institute for Excellence
- 55 Skills for Care
- 56 Skills for Health
- 57 National care home provider (anonymous)
- 58 St. Thomas' Hospital, Modernisation Initiative, London
- 59 The ExtraCare Charitable Trust
- 60 The King's Fund
- 61 The Laurels Care Centre

62 Thomas Pocklington Trust

63 Tunstall Healthcare

64 Uniting Carers

65 University of Stirling, Dementia Services Development centre

66 Unnamed evidence

67 360 Forward

All of the written evidence is available at:

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1061

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