Inquiry of the All-Party Parliamentary Group on Dementia
How to Save Money in Dementia Care and Deliver Better Outcomes for People with Dementia?

Minutes of the oral evidence session held in
Commons Committee Room 15 on 15 March 2011

Before members:
Baroness Greengross (Chair)               Baroness Browning
Stephen Lloyd MP                         David Blunkett MP
Tracey Crouch MP                         Lord Walton
Hazel Blears MP                          Gavin Barwell MP
Anne-Marie Morris MP                     Baroness Blood
Baroness Ritchie

Witnesses:

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 and currently Independent advisor on end of life care to Marie Curie

Samantha Sharp, Chief Policy Advisor, Alzheimer’s Society

Simon Williams, Lead on Dementia for Association of Directors of Adult Social Services (ADASS); Director of Adult Social Services at Merton Council

Dr Dan 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

Time: 15.00 – 17.00
Good afternoon, everybody. Thank you so much for coming to join us. I’m Sally Greengross and I’m privileged to Chair the All-Party Group on Dementia and just for those who don’t know, this is our fourth Inquiry. We’re looking at how to save money in dementia care and deliver improved outcomes both for people with dementia and for their carers. So, today is very important, because this is our first oral evidence day, our first session, and obviously this is a very important issue. Very important. I think people don’t really need to be told that the rising numbers of people living with dementia will grow from 750,000 today to over a million people by 2021. So the numbers of people with dementia are rising significantly to over a million by 2021 and the financial cost of dementia, which at the moment is 20 billion a year, is likely to increase to over 27 billion by 2018, which is very near, and that’s just the cost in money, but the other costs are very difficult to estimate, as we know. The costs in emotion, in care, in people being really brought to a state of acute depression and, indeed, illness because of the strain of caring as well and the emotional costs overall are very, very great.

So, we know that at the moment this issue is of perhaps extreme importance because we’re facing so many cuts in government funding and we don’t want to waste money on care that isn’t as good as it might be, so that people suffer unnecessarily when things could be improved and we know that that has been the case sometimes in the past. So the All-Party Group decided that we could perhaps, through this Inquiry, start the debate on how to deliver better outcomes and improve efficiencies in dementia care while we can highlight some of the best practice through examples that people can draw upon and replicate across the UK. And a report of our findings along with recommendations from the All-Party Group will be published next July. And we’ve received so far, I’m really pleased to say, we’ve received over 200 pieces of evidence from people who have dementia, from their carers, from health and social care workers, from commissioners, from care providers and from a whole range of stakeholders. And today and tomorrow we’re going to hear from a range of eminent people on what they see as the opportunities both for saving money while, at the same time, making the most of existing resources and ensure, as best as we can, quality of life for people with dementia. So thank you very much for joining us, and I’m delighted to turn now to Samantha Sharp, who’s Senior Policy Officer at the Alzheimer’s Society and she’s going to give us an overview of the evidence, the written evidence we’ve received so far.
Overview of Submitted Written Evidence

Samantha Sharp
Senior Policy Officer, Alzheimer’s Society

I. Introduction

Thank you very much. I’m going to talk for about 15 minutes summarising the written evidence that we’ve received so far and there should be a couple of minutes for questions at the end.

II. Evidence-Gathering

The evidence-gathering period was between December and February of this year. We did a number of things to encourage different organisations and individuals to submit evidence. The launch was covered on BBC Breakfast and also local BBC Radio stations. The information about the report for the Inquiry was on the Alzheimer’s Society website. We also targeted attendees of a conference on dementia care and the 50 organisations who are members of the Dementia Action Alliance. To encourage people with dementia and carers to submit evidence, we put information about the Inquiry in the Society’s magazine and online forum and also sent information to United Carers at Dementia UK. Articles by Baroness Greengross also appeared in Nursing Times, on ePolitix and in Government Today.

And, as you’ve heard, we were very pleased at the range of evidence that we received. I worked on the previous report Prepare to Care and I think we received quite a lot more for this Inquiry and also from different and new organisations, which was great. So we received 128 submissions from people with dementia and carers, mainly carers, 92 carers; there were 22 people with dementia and 13 who described themselves as ‘others’ – family, friends and so on. We received 63 submissions from providers and other organisations. I’m only able to give you a very brief summary of some of that evidence today. If you’d like to see a hard copy, then Nicola has one today, is just over there and she’s got a hard copy of all the written evidence.

III. Summary of Evidence from People with Dementia and their Carers

1. Services that Improve Quality of Life

Firstly, I’ll summarise the evidence that we received from people with dementia and their carers. We asked them what activities or services improve the quality of life of the person with dementia and the first thing – well, one of the very key themes that came through in people’s responses was that they wanted services to remember that they’re supporting an individual, so a person with a history, with a family, relationships and likes and dislikes, so the same type of support isn’t going to suit everybody. And really recognising this is the first point – first starting point to getting services in place that are going to make a positive difference to people’s lives and improve quality of life.

In terms of specific services that people talked about, many mentioned social events, such as Alzheimer’s cafes, organised pub lunches, things like this. These were seen as a chance to relax, to
socialise with people in a similar situation, but also to learn from others who are in a similar situation about how they were coping, about how they were dealing with different symptoms and so on, so it could be very helpful in that way.

People also talked about how much they valued key workers, particularly Admiral Nurses, where they had them. They were particularly helpful, because the person and the carer could receive information and advice from people who knew them well; it could be a single point of contact for that person.

Also, enjoyable day opportunities were seen to improve the quality of life of people with dementia and this really comes back to the point about the importance of personalised care. So, people talked about being able to attend art classes which were run for the general public with the support of a befriender. A lot of people talked about going out for walks with befrienders and other supporters and also learning the violin. Day centres that provided a good range of activities were also thought to improve quality of life.

And carer support was seen to be essential to improving quality of life for the person with dementia and their carer, particularly emotional support a lot of people talked about and also good quality respite.

2. Services that are not useful or enjoyable

Now, secondly, we asked people if there were any services or activities currently provided for people with dementia that weren’t useful or enjoyable and a lot of people talked about poor quality home care and one of the key problems was staff who weren’t very well trained in supporting people with dementia, but also home care that was rushed, people who didn’t turn up on time and things like that. And these sorts of problems actually made people’s lives more difficult rather than actually improving their well-being and quality of life.

And a number of people mentioned day centres and this again comes back to the point about personalised care. If you’re not really a person who likes to join in with group activities, then day centres aren’t going to be the thing for you and a lot of people talked about the distress that the person with dementia experienced when having to go off to the day centre. So although they provided some sort of a break, it wasn’t really quality respite and it wasn’t useful for anybody.

3. How to spend money more effectively

We asked people with dementia and carers if they had any ideas about how to spend money that is currently spent on support and services in a more effective way and again, a lot of people talked about key workers. They felt that a key worker would help to reduce the number of assessments. People often experienced, as you know, duplication in assessments. It was also felt a key worker could coordinate all the different parts of their care package in a better way and also spot problems early, and this was particularly for people with dementia who were living alone. If a key worker was able to spot a problem early, they could do something to sort it out and, as one carer said, ‘A stitch in time saves nine.’

Also, people talked about better staff training for the whole range of staff that they come into contact with, so that they can provide better quality care and more effective care. And people talked about whether it would be possible to use volunteers more in dementia services; for example, in inspection services and also in giving advice, but also existing community resources –
so being able to go out and visit free entry museums, and also whether it would be possible for people with dementia to help to tend public gardens if gardening was one of their interests.

And more ideas that people have for spending money better was: increase support for carers so that they could carry on caring for the person at home where that was what they both wanted; and also funding research into preventing dementia. But a number of people argued that it wasn’t possible to save money in dementia care because there was a real dearth of services at the moment, so it was more a question of how to spend more money in dementia care rather than less.

IV. Summary of Evidence from Providers and Other Stakeholders

1. Opportunities to save money and ensure quality of life

Now I’m going to summarise the evidence from providers and other stakeholders. We asked these organisations what they thought were the best opportunities to save money, to ensure quality of life for people with dementia in hospitals, their own homes and care homes. Now, many respondents pointed out the overarching theme across all these settings and they argued that really you needed to consider the system of dementia care as a whole rather than break it down into these constituent parts, because changes in each different part of the care system would impact on other parts, so you needed to think of the system as a whole.

A lot of people talked about the importance of getting the physical environment right as an environment that was badly designed for people with dementia could cause problems with potential risks to people’s well-being and also associated costs. So, for example, poor lighting can increase the risk of falls and bad signage can make it more difficult for people to find and use the toilets. And the King’s Fund also talked a lot about their Healing Environment Programme and they found a well designed environment for people with dementia can reduce challenging behaviour, agitation and aggression, for example, and can increase uptake of activities and also staff morale and retention with obvious cost savings.

Respondents also talked about the need for staff training, so that staff can actually provide much more productive and efficient care. And a number of people talked about the value of dementia champions in different settings; people who can act as leaders in dementia care. This can be a very cost effective way of training and supporting other staff to improve practice through modelling and working with other staff.

2. Hospitals

Turning to opportunities to save money but ensure quality of life in hospitals, a lot of people talked about how the hospital was a very problematic environment for people with dementia, so really we need to focus on how to avoid admission and ensure they did not have to stay. But for people who had dementia who were in hospital, it was important to get rates of recognition up from where they were at the moment and this was about sharing information with primary care and also being able to identify and assess people with suspected dementia once they were in the hospital. And once you’ve recognised who has dementia then it’s about getting them on the right care pathway and tailoring their care to their needs. But also, basic care for people with dementia in hospitals has to be improved; for example, avoiding bedsores, meeting people’s needs for nutrition and hydration and also preventing delirium.
Other ideas people had for opportunities to save money in hospitals include better access to old age psychiatric liaison teams for helping to assess people with suspected dementia, care planning, supporting staff and also supporting the discharge process. And better discharge planning, early discharge planning in particular was highlighted, to avoid delays in discharge, make sure people get into the right setting as soon as they can, and to avoid readmission.

People thought volunteers could be used within the hospital; for example, at meal times and in supporting people to take part in activities. And there was also an argument for more joint working; for example, wards that were jointly run by old age psychiatrists and geriatricians, so meeting a whole range of people’s needs.

3. **Own Homes**

Turning to opportunities to save money but ensure quality of life for people with dementia in their own homes. A lot of people talked about how community support, good quality comprehensive community support was vital to avoid unnecessary admission into hospital or residential care. And again, better case identification was very important, so that good care planning could take place and also early intervention; a number of people highlighted Sube Banerjee’s work on the economic metric which showed early intervention could be cost effective. Also, maintaining physical health, so regular reviews to make sure there was no accelerated decline of people’s cognitive and physical health. Again, people talked about the need to support carers and education programmes for carer was raised by a number of people as an opportunity, particularly in supporting carers to deal with behavioural symptoms as this can often be a risk factor for early institutionalisation. And telecare was mentioned as an opportunity to save money; for example, GPS systems for people who may leave their homes and also medication dispensers.

4. **Care Homes**

And opportunities to save money but ensure quality of life for people with dementia in care homes, and it was pointed out that although admission to care homes or delay in admission to care homes is often seen as desirable, care homes can be the best place for many people and make a big difference to their quality of life, particularly people who are at risk of isolation.

Many people discussed the need to reduce admissions from care homes into hospital and they really focused on how care homes should be better able to deal with medical issues within the home; for example, pain management and end of life care. But to do this they do need more support from multidisciplinary inreach teams and also from GPs and geriatricians. The British Geriatric Society said that particularly if hospital beds were to be closing then there could be a much greater role for geriatricians working much more closely with the care home sector. And the Alzheimer’s Society also mentioned the Dutch example whereby the care homes have elderly care physicians on the staff team and they have a very low rate of admission from care homes into hospitals.

5. **Barriers**

We asked people what do they see as the barrier to doing these things and the lack of a whole systems approach and joint working was really one of the things mentioned by a lot of people. Although different parts of the system do impact on each other, a lot of the time things are thought about separately rather than looking at how different parts of the system can support each other. And the lack of pooled budgets here was one of the problems. Often money spent, say, on community care, good community care can lead to savings in the acute sector, but it’s very difficult
to move money from the acute sector into community care to get that support in place, and that was a major barrier. But also, the health and social care system has many competing agendas within it and dementia has been a relatively low priority. And also the tendency has been to wait until a crisis occurs in somebody’s situation and then putting high cost, high level care in then and it’s difficult to change those patterns of working.

6. Examples of high quality care

We asked respondents if they had examples of services that provide high quality care and support for people with dementia in a way that makes best use of resources and we got many different examples and they varied in the level of detail that they had. Some had a lot of information about costs; some were in quite early stages, so they didn’t have very much evidence on costs and outcomes so far.

Some of the ideas that we received were: one County Council had a care home forum, so the care homes in that area came together, they swapped ideas, shared good practice, but they also heard from high profile speakers and trainers and this was a cost effective way of training and also learning about good practice.

Another area used volunteers, ex-carer volunteers to provide support to people recently diagnosed or recently new to caring, and they gave advice and also talked about things such as advanced decision making and so on.

Another service that was seen to provide high quality care and make good use of resources was a liaison palliative care nurse who worked with care homes in her local area and as well as direct patient contact she also provided training and support to care home staff, so that they could provide good quality end of life care themselves in a cost effective way and also in a way that provided good quality care to the person with dementia.

In the Isle of Wight, and I’m sure we’ll hear more of this from Dan Harwood later on, an anaesthetist with an interest in dementia has done some work on pre-surgery assessments to make sure that there are no ill effects following surgery and anaesthesia. And they also have a 24-hour helpline for residential care home staff, particularly to advise on dealing with behavioural symptoms without having to resort anti-psychotics.

BUPA have also done some work on improving case identification, so merging the GP-held records with other records and this has doubled the number of people in a particular area identified to have dementia. And BUPA explained that for those patients who were on the GP dementia register, costs were much lower, probably because they were reviewed much more regularly. Obviously a tool for better case identification would, hopefully, save costs.

Baroness Greengross

It was fantastic and a wonderful summary of a lot of very interesting points raised by the stakeholders who were asked.

So, are there one or two questions people would like to ask Samantha?
Questions and Answers

Baroness Blood

Yes, could I ask given that this survey was mainly around carers and people with dementia, was there any survey around GPs? My understanding on the ground is they’re the first point of contact and if they don’t understand the problem that person just goes into outer space.

Samantha Sharp

Yes, no, you’re right. I think we received just a very small number of submissions from GPs and probably it would have been very useful to hear more because, as you say, they are the first point of contact, but we can have a look through the evidence and pick out the bits that we received from GPs and see what their ideas were and what they had to say.

Baroness Blood

Okay, thank you.

Lord Walton

Do you mind if I just ask a couple of questions? John Walton, I’m a former neurologist and I’ve had an interest in dementia for many, many years. I’m also a patron of the North Northumberland Day Hospices and St Oswald’s in Newcastle. Now, some years ago, I lived for a time in Burford in the Cotswolds where, in the Community Hospital there, there was a quite outstanding community programme called SPECAL, which they organised from the Burford Community Hospital, which had, in fact, closed, but SPECAL continued to use the premises for some years, but I gather it’s now disappeared. Have you any idea what’s happened to that particular service, because it was very effective as a day centre for patients with dementia in the Cotswold area.

Samantha Sharp

I know that people are still using the SPECAL approach in dementia care and a few of the carer respondents wrote and said how they’d found it very helpful, but I don’t know if it’s still running from a day centre. I don’t know if any of my colleagues know about that day centre and SPECAL. No, I’m sorry, we don’t know. We can check that for you.

Lord Walton

I’ll be asking some questions about early diagnosis later.

Baroness Greengross

Well, I think that’s absolutely brilliant, because we’ve had a very good insight, I think, into what a lot of people feel are priorities and thank you so much for explaining this and describing what’s come in so very clearly, and it was great.
I. Introduction

Thank you very much. I was asked by the Alzheimer’s Society to look at some of the economics evidence. I work as an economist at LSE and the Institute of Psychiatry and have worked with the Alzheimer’s Society in the dementia area, and so, with my colleagues, we’ve been looking at what evidence there is on the cost of dementia, particularly on the cost savings that might come from better strategies and the cost effectiveness of those strategies. So I’m going to quickly zip through what we’ve found so far.

II. Cost Effectiveness

I need to explain a bit about the cost effectiveness just because it’s going to become an issue, I think, towards the end of what I say and also a big issue more generally. What cost effectiveness means usually is that if you do something which has better outcomes, generates better outcomes, it nevertheless costs you more money. So it may be that it’s not going to be cost saving, but the benefits, the outcomes you get are worth that extra cost, and that’s the sort of thing that NICE looks at and one of the reasons why NICE gets on the front page of the Daily Mail when it suggests that it’s not doing. But that’s going to become a big issue, I think, in the dementia area, so I’ll come back to that.

III. Main Costs

We looked at the main costs and I think the thing to emphasise is that a very large proportion of the overall cost of dementia is the hidden element that falls to carers. The time that carers spend, the strain on them, the impacts on their health, and the most recent estimate from a group of economists at Oxford suggested that the informal care cost was 55% of the total. Now, there’s lots of controversy about whether that’s a real cost and so on and I’ll come back to that as well, but we have to remember that a large part of the economic impact is not picked up by the NHS or local authority budget.
IV. Strategies for Addressing Costs

1. Evidence Search

What strategies then are there for addressing this high costs, there are other costs that Baroness Greengross mentioned at the beginning, and from promoting cost effectiveness? And we looked at whatever evidence we could find. We did lots of searching and we looked at prevention of the illness, at better or earlier diagnosis, of interventions to delay progression of the disease, interventions to reduce the consequences of the symptoms, support for carers, improvement of cross-agency working and better end of life care, and I’m just going to summarise what we found for where we found it. So I will say nothing about end of life care because we found nothing on the economics of it. We found nothing really substantial on prevention. So I’ll just summarise what we did find, but I just want to make three quick points before I just go into their areas about the problems with economic evidence:

One is that it doesn’t travel very well between countries and so what’s cost effective in Baltimore is not going to be cost effective necessarily in Balham or Barnsley. But the point is that the clinical evidence may travel between countries quite well; cost effectiveness evidence doesn’t because the health systems or care systems can be different, so that’s a bit of a problem.

The second thing to watch out for is what economists would call the perspective of the study – what costs and outcomes are we looking at? Are we looking just at the public sector costs? Are we looking at the whole societal costs? Are we looking only at the health service costs? There’s a whole range of different ways we could define the costs and I think in an area like dementia we have to be very careful to look at that very broad impact given what we know about the consequences for families and for others.

And then the third point is what I alluded to earlier about the costing of informal care, family care. It’s not at all straightforward and it’s not at all uncontroversial, so it’s a difficult issue and I’ll come back to that at the end.

So, what did we find? I’m going to just break it into – I’m not going to go through this in any detail – break it into four areas.

2. Drug Therapy

Firstly, on drugs, there’s lots of evidence, lots of economic evidence. They are most of it generated by the pharmaceutical industry about which one may have opinions. The evidence is broadly supportive of some drug therapies for some people at various stages of the illness and NICE have commissioned a marvellous review which is really very, very helpful in this area. So I think we do have some evidence that there are some drug therapies that work. There is a question around the antipsychotic drugs that are sometimes used because they can have not very nice side effects, but there are some dementia-specific drugs which are looking like they will be cost effective in some patient groups.

3. Non-Drug Therapies for Patients

The second group is non-pharmacological, non-drug therapies for patients and there, there is a little bit of 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.

Exercise programmes have been talked about a lot as preventive measures; we couldn’t find economic evidence at all.

And then there’s something called a tailored activity programme, which has been studied in the States, which is delivered by occupational therapists in people’s homes and it’s meant to address the problem that dementia patients often have that as their illness progresses they become less tolerant to environmental stimuli and it’s trying to help those patients to overcome that problem. And that looked both effective and suggested it might be cost effective, so there’s a bit of evidence there.

4. Non-Drug Therapies for Carers

Then we looked at non-drug therapies for carers and certainly there’s some evidence about counselling and support for carers which can delay the movement of an individual with dementia into full-time care, which often means going into a care home or hospital. There’s some evidence in support of respite care, not as strong as we thought there might be, and there’s some evidence in support of psycho-educational support, giving carers a better understanding of what dementia means and helping them to develop strategies to deal with their responsibilities. So, some evidence.

5. Organisation of Care and Support

And then the fourth area is what we’ve called organisation of care and support and here there are three areas I would highlight. One is the use of direct payments, which you mentioned, and people being given the budgets for their care, personal budgets. Personal health budgets are being trialled at the moment where the evidence is encouraging, particularly for dementia patients; when the budget gets handed to the carer, it looks to be encouraging. And then Samantha mentioned the key worker idea and certainly some evidence in support of what’s called coordinated care management, this sort of community-based support in a coordinated way perhaps across different areas.

And then the third area I’ll just mention is better care for co-morbid conditions. We did some work a while ago for the NAO actually, looking at people with dementia who fracture their hip, fracture their neck of femur, who stay in hospital for much, much longer than people without dementia. So it’s often these comorbid conditions which hugely seem to complicate the service responses.

V. Barriers to Better Quality of Life or Better Efficiency

Final comments. I was asked to look at barriers to better quality of life or better efficiency and I’ll just pick up on five:

- One of them is reductions in budgets, obviously, and that might change the eligibility threshold for people getting council-funded care. It may not affect a lot of people with dementia, but it will affect other people and it may be that budgets for prevention get cut, but maybe not in the dementia area, but it will affect other people. And so I think dementia services will be facing even more competition for funding support in the new environment, so that’s one point.
The second one is the point made earlier about whole system approaches and budget silos we still haven’t sorted out. I always joke in presentations that there’s a Nobel Prize for coordinated working but it’s never been awarded and nobody’s yet found a way of bringing health and social care services together really on a long term successful basis, and it is a big challenge to do that.

The third area is about hidden impacts. I mentioned the big costs to carers. One of the problems I think dementia faces is that the hidden impacts – most health problems have hidden impacts, but the hidden impacts in the dementia area are not valued very highly. So in the area of depression, for example, the hidden impact is people can’t work and that has a big impact on the economy and so there’s some incentive for DWP to do something about it. But for carers, they’re not often looking to work, they’re not being prevented from working by their caring responsibilities and therefore the impact on them may not be valued by decision makers.

The fourth barrier I think is reluctance to take up evidence-based interventions. Direct payments, for example, the evidence is pretty good, but there’s still very, very low take up, which I think is at least partly due – I know is partly due to professional conservatism; care managers are very hesitant about recommending it, I’m afraid, in many areas. And cognitive stimulation therapy, I had an email from somebody this morning who had done a Freedom of Information request and found that 10% 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.

And then the final point is about this cost effectiveness issue I mentioned at the beginning, that it’s all very well saying ‘this intervention is more costly and it’s also more effective and the effects are worth spending additional money’ and that’s the sort of argument that NICE get into very often, but within increasing pressure on budgets there’ll be less willingness to pay for things which are not cost-saving. So unless you can demonstrate cost savings it’s going to be tougher, I think, to argue the case for some therapies.

Baroness Greengross

Martin, packed with information as always, thank you so much. Can we now turn to Karen, Karen Taylor? Will you tell us, first, who you are, because both your careers are very important and relevant to this?
NAO Reports on Dementia Services

Karen Taylor
Independent Consultant in End of Life Care and Early Diagnosis, former Director of Health Value for Money, NAO

I. Introduction

Certainly and, yes, I should stress that I am not an expert in dementia and I haven’t worked with people with dementia or their carers. I’m coming to you to talk to you today from the perspective that for the last 13 years I worked at the National Audit Office as the director of health value for money audit and in that capacity I did two investigations of dementia services and the way that they were arranged and provided from the national perspective, but also drilling down to the local delivery. The first report was in 2007 and it was really sort of the first report to raise the importance of this issue and the huge cost and lack of attention that has been given to this subject to Parliament in terms of from the National Audit Office. There were other reports from the Alzheimer’s Society, the London School of Economics, its report on the costs of dementia, but it was bringing all of the information and evidence together in a report to Parliament.

In response to that first report the Department of Health announced the development of a national dementia strategy to raise the priority and profile being given to dementia and to have a more consistent approach across the country. With that dementia strategy was an implementation plan which, at the time, we judged to be lacking in detail and relevant information and the Committee of Public Accounts, who takes evidence on the National Audit Office’s reports, they felt that the response to the strategy was both too late, it had been delayed, and that it wasn’t giving dementia the priority that they’d been led to believe that it would get at their previous hearing. So they asked for a follow-up report, which we did in 2009. So quite soon after the strategy we started to look at whether or not the strategy was going to address the concerns we’d raised and we published that report in January 2010.

One issue that was very important at that point was that when we looked at other strategies, and we’ve done reports on end of life care, neonatal service and stroke and cancer services, all of the strategies that seemed to be implemented more effectively had one thing in common. They had several things in common, but one of the important things was having a national lead to drive dementia, to drive improvements and whilst that had been a recommendation in the 2008 report of the Public Accounts Committee, in January 2010 when we published the follow-up report there still hadn’t been an appointment. An appointment was made shortly thereafter and we have followed progress since then.

I should stress that I no longer work at the National Audit Office, but I have got their agreement that I can come and talk to you today about the work we did and the findings in those reports in order that we get that evidence base which, from what I’ve heard already, actually has the same findings as we’ve just heard from the carers and people with dementia survey and the lack of any much more robust evidence on costings. So there’s a lot of evidence underpinning those two reports that I think would be useful to your Inquiry.
II. Five Key Points

I was asked to highlight five key points that I thought ought to be considered as part of your focus and these are ones taken from the two reports.

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 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 a primary care trust as commissioners and hospital and others as providers, because they weren’t being measured in terms of how well they were implementing improvements, and also the point about the national leadership.

The second point is just the fact that historically, as you all know, dementia suffers from poor awareness and understanding combined with the stigmas attached to both old age and mental health, and much of the support and understanding is vested in the voluntary sector, but the NHS still largely appears to be neglecting staff development and understanding. Now, there are lots of examples of good practice. There are 13 examples of good practice in the two reports we published, 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’s 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.

Some additional money was announced to support the implementation of the strategy. It was 69 million in the first year and a similar amount, 90 million, in the second year, but when we asked commissioners how they were using this extra money most didn’t even know they’d been given the extra money, because it had been given in the baseline, in the bottom line, and they certainly couldn’t tell us how they were using it. Now, an audit has been taking place and I haven’t seen the results of that audit and maybe some of our other experts will be able to inform you as to what that’s shown, but our finding was that primary care trusts just hadn’t raised that priority that they were giving to commissioning services for dementia.

Early diagnosis, as we’ve heard, is crucial and in our 2007 report we amassed the information from lots of experts who felt unequivocally that early diagnosis and targeted interventions was cost effective. But, again, too few people are still being diagnosed early enough or, if they are being diagnosed, they are not being adequately supported, both the people with dementia and their carers, as the support services in the community is simply not sufficient.

And, finally, achieving the dementia strategy requires coordination 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 cost savings in one care setting will likely not benefit that setting, but will be realised in another setting. 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 and I suppose that’s my final point, really, overarchsing point. 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 eight 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.

Questions and Answers

Baroness Greengross

Thank you very much, Karen. That was packed with material we need, I think. Thank you very much indeed. We’ve now got time to ask questions of our two initial witnesses, so, Baroness Browning, would you – not everybody’s got a badge and not everybody will be able to see who people are, so would you mind saying who you are when you ask a question?

Baroness Browning

It’s Baroness Browning. I had the pleasure of serving on the Public Accounts Committee when we received your reports and could I just ask both you and Professor Knapp something? In that initial report to the Public Accounts Committee from the National Audit Office you quoted a document that Professor Knapp had already published. It was the Knapp et al 2007 Dementia International Comparisons and Professor Knapp’s just told us it’s quite difficult to make these international comparisons, but there were four key things at which the UK came out worst compared to other major European countries and I’ll just, if I may, just ask you about two of them. One of them said that the proportion of doctors who agreed that early treatment can delay progression of Alzheimer’s disease was the worst in the UK compared to other countries such as France, Germany, Italy and Spain. Only 68% of UK doctors apparently agreed early treatment can delay progression of Alzheimer’s and I really do feel, Chairman, that at the heart of this is getting in early with early diagnosis and early interventions and, at the same time, we were the worst for the time taken to diagnose Alzheimer’s disease after the first symptoms were noticed.

Now, we’ve had this strategy in place; I know it’s a five-year strategy, but it’s been in place now for two years. Can either of you give us any hope and confidence that that appalling statistic, comparative statistic, I know, has improved in any way since all of this had a light shone on it two or three years ago?

Karen Taylor

I’ll answer first. I’ve just passed Martin the appendix that summarised the international work back in 2007. I don’t know any more up to date information on international comparisons, but in 2009 we did do a re-survey – and this is a question that was asked earlier as well. We surveyed 1,000 GPs in 2007 to ask a number of questions about their confidence, their awareness, whether they felt comfortable diagnosing people with dementia, whether they felt they could provide support. It was a survey that had originally been done by the Audit Commission and we repeated that in 2009, so we had three years of data and that does show an improvement in GPs’ awareness, confidence to diagnose, but on one crucial question, which is whether they thought early diagnosis was worthwhile, the response was still below 60%. So, even despite all the publicity, despite the fact that the strategy had been published by then there’s still 40% who do not think early diagnosis is necessarily a good thing.
Professor Martin Knapp

The only thing I’d add to that is 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. So I think there probably is still a reluctance there; I haven’t got any more up to date information.

Just to say on international comparisons, the point I was trying to make was that it’s the narrow, shall we say, economic evidence doesn’t travel very well, but I think the other comparisons are very worthwhile doing and there’s been a report – I think your organisation, Baroness Greengross, produced a report recently with new comparisons of dementia care systems across countries, so I think we’re getting a better understanding of what’s going on.

Karen Taylor

Could I just correct, because I should correct myself. Providing a patient with a diagnosis is usually more helpful than harmful is the one that’s less than 60%. It improved from 51% of GPs to 58% of GPs. In beneficial to make early diagnosis the improvement is much more marked, actually; it’s gone from 68 to 77%, so it’s better there. It’s just that they don’t actually think it’s that helpful to give the diagnosis, largely, from the feedback we received, because they don’t have or don’t know what support to provide or how to point the people in the direction of the support, which again, there’s lots of information out there, it’s just that they’re not accessing it.

Baroness Greengross

Can I, Angela, just say that Martin mentioned that report; it’s produced by the ILC UK, but for the ILC Global Alliance and it’s on the website. Thank you for mentioning it. But it does give those comparisons of information we had.

Can I turn to Lord Walton?

Lord Walton

Yes, may I come in again? John Walton, cross-bench peer and former neurologist. I’m so glad that in these three very interesting talks that Professor Knapp talked about the crucial importance of the measures which are universally needed for patients with dementia of all types. And he’s absolutely right that cognitive stimulation therapy and supervised activity are among those. They require considerable skills and that was why I raised this issue of SPECAL, because those were used at that particular place.

But the other important matter is, of course, that dementia is a group of diseases of which Alzheimer’s is the commonest. I mean there’s, of course, vascular dementia resulting from repeated minor strokes; there is also frontal temporal dementia; there is Lewy body disease. The crucial importance is that the drug therapy that we have available at the moment is only effective, for practical purposes, in Alzheimer’s disease and we do not yet have an accurate diagnostic marker, though there are works – there is work going on at the moment which suggests the possibility that fractions of the amyloid protein may be present in the cerebrospinal fluid and may ultimately result in an accurate diagnostic test. I was involved with the Perrys originally and their work in Newcastle on the introduction of the cholinergic drugs and one of the problems when it
was mentioned that we were slow and the doctors were very slow to adopt the use of these cholinergic remedies based upon that work and the work of Professor Bowen was because NICE in the early days refused to recommend the use of these drugs in patient with early Alzheimer’s disease. And I think that was a serious mistake. Subsequently, they’ve changed their minds and I think that’s important, but it’s also crucially important to recognise that as a result of research there are other forms of therapy which are not too far distant and that’s why, I think, the issue of early diagnosis and accurate diagnosis is so crucial. But as you say, the important issues, once the diagnosis has been made, is the management and that is, of course, things that you’ve highlighted with the techniques which are so valuable.

**Professor Martin Knapp**

I’ll just say one quick comment, I think, which is that I think why we need to take cognitive stimulation therapy and similar therapies very seriously is that care homes, with or without very much in the way of skilled medical input, are the frontline – well, maybe not the frontline, but they are a key provider of services to people with dementia. We did a quick calculation that 50 years ago it was about 2% or 3% of all care home residents had dementia and now it’s about 50 to 60% of care home residents have dementia. We have to make sure that the staff in those homes have the right skills to respond to the needs of residents.

**David Blunkett**

I daren’t even begin to think about what GP commissioning will mean for all this, given what’s been said this afternoon. Karen Taylor, can I just ask you a leading question? I mean from your experience at the National Audit Office, we have an obsession at the moment in this country of not ring-fencing resources from national level. What would your personal view have been if the money that had been allocated over the two years initially had, for those two years, not necessarily in perpetuity, been ring-fenced specifically for dementia care and support, so that there was no question whatsoever that it could just be absorbed into the general budget?

And I’d like to ask Martin, if you don’t mind, about the issue of interventions that you might have thought were helpful. Is it not the case that some interventions, like respite care, help the carers to survive but they might not actually be beneficial to the dementia sufferer and balancing these two is the really difficult issue that originally we had difficulties with NICE over in terms of what is a beneficial social outcome as well as a medical one.

**Karen Taylor**

Obviously, I can’t say what would have happened if they had ring-fenced the money for dementia, but what I can say is that our work on stroke services, where they did ring fence money for stroke rehabilitation and where although they didn’t ring fence the money for primary care to commission more effective stroke services, they were told that they – sorry, so that’s on stroke where they ring-fenced it and therefore they were able to monitor it, local authorities who were given the money knew that they had to account for spending it, and so therefore they did spend it on rehabilitation services. There is now a question with that money being – it was only for two years, whether those rehabilitation services will be maintained, but it did allow you to see a definite shift in the services available.

On end of life care, although they didn’t ring fund the money to primary care trusts to commission more effective end of life care services, what they were told was that they had to report back each
year on how that money was being spent and what they were spending it on. So there is an audit trail, as such, as to how that money was spent.

So it doesn’t necessarily have to be ring-fenced as longs as there’s more clarity about saying you have to justify, demonstrate how you spend it. So it’s ring-fencing in all but name there. I think without the ring fencing it is too easy for the money just to disappear into a pot and whoever’s shouting loudest in that particular locality will get more priority.

**Baroness Greengross**

Thank you. David, you wanted to come back.

**David Blunkett**

No, I just wanted to reflect on carers

**Professor Martin Knapp**

Yes. I think there’s been a hesitation or reluctance among the researchers to look at the effect on carers until relatively recently. I think we have much better evidence now. In the original NICE appraisal that was referred to earlier, the carer impact was fairly conspicuous by its absence. I think NICE certainly do look at that now and give that a lot of attention, so I think we’re beginning to get a better evidence base on that and one quick example of that: in the pilot programme for individual budgets, which are the forerunners to personal budgets, the impact on older people of these personal budgets as individual budgets was not terribly positive, but it was very positive for the carers of older people and so I think we have to just remember that sometimes the impacts are not evenly spread between those two groups.

**Karen Taylor**

Could I just add on that? In our survey of – it was a web-based survey of carers and people with dementia, one of the things that they raised was that having access to that respite care allowed them to keep their loved ones with dementia at home for longer and it was usually a crisis in the carer that precipitated entry to a care home rather than a crisis with the person with dementia.

**Tracey Crouch**

Tracey Crouch, the MP for Chatham and Aylesford and, Professor Knapp, you mentioned two things, one in particular got some very heavy nodding from this side of the table, which was about better care for comorbid conditions and I just wondered if you could expand on your findings on that. Clearly, there are concerns about the cost of care in hospitals and I do think it is linked into something that the evidence has found around dementia champions and their role on hospital wards. I’d be grateful for your comments on that.

And secondly, we’ve already spoken about CST. You said in your evidence or your submission to the Committee that it was broadly promising. I just wonder if there are any specific figures that you can add to that.
Professor Martin Knapp

Okay, can I just go to the second one first, because it’s easier? Broadly promising because the cost effectiveness study was led by me, so I was being a bit careful about how I trumpeted it. But I mean there was an evaluation delivering group-based CST in day centres and in care homes led by Martin Orrell, a Professor at UCL, and they found good outcomes – I haven’t got the outcome stuff in front of me here. In the cost effectiveness evaluation we found that there were noticeable improvements in quality of life for these individuals and it was not more expensive. It wasn’t pushing up the cost. There was a slightly higher cost of delivering the CST in these facilities, but there was a small reduction in the use of services even in a relatively short space of time. What we need is longer term evidence. We need evidence on whether this therapy delivered individually would be even more effective and, coincidentally, there are studies under way now which are looking at those things and they have economic evidence. So I think we will have some evidence quite soon on those and certainly on the longer term evidence that – those results should be around within a year or so.

On the comorbid conditions, there’s a study which has just recently been finished led by Sube Banerjee, who was mentioned earlier, looking at people with comorbid dementia and depression and I’m not sure I’m allowed to say what the results are. We haven’t finished the cost effectiveness results, we’re doing those, but on the outcome side they didn’t find difference between different drug therapies in that particular case, but the cost effectiveness evidence we don’t know yet, so there might be something there.

On the hip fracture one, the work that we’ve done pointed to very clear advantages if people took account of what is known about good practice. So whether it’s ward-based good practice or other forms of good practice, it’s just that that good practice had not been spread out to many other places. So the work we did was commissioned by the National Audit Office some years ago and we’d like to make that more widely available, I guess.

Tracey Crouch

Could I just come back? Do you think there is value in providing almost a place in between the hospital ward and the care home or the home where somebody who has had to go to hospital with an acute need can then sort of almost be transferred into a second place where they can have – they can continue with their acute care, but they’re not then sort of, you know, automatically let to go back to the care home or to their home without being sort of, you know, completely fixed physically, but are not blocking up the hospital and therefore costing more, as it were? Sorry, that sounds incredibly insensitive, but with all the trouble that having dementia has that causes extra stress – financial stress in hospitals.

Professor Martin Knapp

I think it is. I think the difficulty often is 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. And with dementia it’s
difficult, because of this age-old problem of health budgets and social services budgets getting in the way of sometimes sensible movements between different settings.

**Baroness Blood**

Can I just add that we have – I’m from Northern Ireland, we have a facility at home that does that that’s called ‘hospital to home’ and sometimes someone sent to hospital, say with a broken hip, they’re then moved into a care home on the strict understanding they’ll only be there for three/four weeks and that gives the family of carer a chance to prepare a package around the question of coming to their own home.

**Karen Taylor**

Can I just say that we identified in our 2007 report a case study of exactly that – early supported discharge to both - either to the home or into an intermediary step to try and facilitate that, particularly for people with a fractured neck of femur. So I think there are examples of that and a hospital that I am now a non-executive director on – at has invested in hospital at home and also has bought some beds in an intermediary care home for such purposes.

**Hazel Blears**

Yes, I just want to follow up that issue really and my apologies for being a little late and it might be that what I’m raising will also come up in the next sessions. And it’s really in the evidence that we’ve received from people time and time again people are saying the lack of an integrated holistic, whole systems approach to this issue is a real barrier. And I just wonder what your view is of the fact that if we don’t have targets and we don’t have ring-fencing then where is the pressure within the system to drive people together? For me, part of that is the individual budget, which can drive the system to provide a more coherent, integrated offer for people, but I just wonder how powerful that is, because it’s early days for those individual budgets and it just strikes me that there’s no grit in the system as it stands at the moment to drive people together. It might be that the financial austerity is a big driver, because if you’ve got less money you’ve got to spend it in a better way, but I don’t know that there are any real levers and I just wondered what your view was of that.

**Professor Martin Knapp**

I share exactly that view. I think that individual budgets, direct payments, personal budgets I think are one of the most promising budgets 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.

**Karen Taylor**

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.

**Gavin Barwell**

My name’s Gavin Barwell; I’m the Member of Parliament for Croydon Central. Mine’s a very simple question actually, just to wrap things up and it’s to Karen. In your remarks you referred to a project in Lincolnshire where sums of money had been released from acute hospital care. Can you just tell us a little bit more about that and, also, I’d be interested to know what you think are the barriers that have prevented that kind of work happening elsewhere around the country? Why did it happen in Lincolnshire and has not been picked up?

**Karen Taylor**

I remember at the time thinking that the chief executive of the Lincolnshire Hospital Trust was very brave to allow the exposure that we brought to what was happening in his hospital, because what we did is we looked at how many patients were in a hospital bed with dementia who had no medical needs to be there. We employed consultants with the expertise to do this and whether there were, within the Lincolnshire environment, other settings where these people could have been cared for. And it identified that there were about 40% of patients with dementia in hospital beds with no medical need to be there and that there were the facilities elsewhere, including in their own care homes, hospices, etc, or support available in the community. And that’s what they did: he agreed to give up some of his budget from the hospital to invest in supporting in the care home and we went back and looked at progress when we did the 2009 report and saw that 6.5 million had been released. They’re both written up in our reports.

**Gavin Barwell**

And 40% of what?

**Karen Taylor**

Patients.

**Gavin Barwell**

Forty percent of patients in that hospital or...?

**Karen Taylor**

Forty percent of patients in the hospital with dementia that were identified had no medical need to be in the hospital bed.

**Baroness Greengross**

That’s amazing. Thank you. Can I think you, Karen, and thank you, Martin, very much? Extremely interesting. Thank you.
We now have four key witnesses to speak with us and I’m going to ask you each, if I may, to introduce yourselves and then give us your comments and then we will fire questions at you. So could I start with Simon Williams?

Oral Evidence from ADASS

Simon Williams
Dementia Lead for Association of Directors of Adult Social Services (ADASS) and Director of Adult Social Services, Merton Council

I. Introduction

Good afternoon. I’m here representing ADASS, which is an organisation of 150 directors of adult social services across England. Essentially, we contribute to policy formation nationally and seek to share good practice. I’ve been in this role leading on dementia for nearly two years.

II. Money Wasters

1. Crisis

Thinking about the question around what are the main opportunities, I’m not an expert in this area, but it seems to me increasingly that you could say there are three main money wasters, and they all begin with C and they are, I would say, crisis, continuity and control. I would say that, because if you look at a lot of these areas 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.

2. Continuity

The second area is we fail to treat the person with dementia as a whole person and we have a whole number of very specialist fragmented interventions, whether they’re in hospital or in the community and that wastes a lot of money as well.

3. Control

And the third area, around control, is that we make the wrong assumptions that a diagnosis of dementia is often seen as a sort of way that you lose control of your life, and that partly why I think GPs are so reluctant to give that diagnosis, whereas what we need to be about is enabling people to keep as much control of their lives for as long as possible and, actually, when we give people that opportunity actually people come up with very cost effective solutions.

Just looking at some – I’m not going to repeat the excellent presentations –
Baroness Greengross

Sorry, I don’t want to interrupt too much, Simon, but with our four presenters, can you make your comments fairly brief, because I’ve just been told that this room is booked from 17.00, so we have to ask you to be brief, because lots of people want to ask you questions.

Simon Williams

I was about to say I was not going to repeat what Samantha said about the main opportunities to save money, because I think that’s been well said already.

III. Creating Leverage

Finally, how we can maybe create some leverage to take this forward. I think the first area would be around ensuring that dementia is mainstreamed into initiatives such as personalisation, personal budgets, long term conditions.

The second area is within ADASS we’re developing our own useful resources framework, which we’ll be launching later this year and the evidence on dementia will be accessible to councils.

The third area, this is really the Alzheimer’s Society have led this, the Dementia Action Alliance, which begins to get around this lack of a kind of central ring fence strategy. This is kind of an Alliance of the willing and we had a really good meeting last week; I think we can do a lot of good work together.

And probably the last area, I think it has to be all about local alliances and almost, in a sense, mirroring what’s happening nationally, and I think the areas that will make the most rapid progress are, essentially, areas where there’s a strong voice of the customer, and particularly, I think, where commissioners, given that we’re all going through change at the moment, will mandate experts to deliver change. And you’re probably going to hear from some very expert providers in a minute and I think there’s a lot of room to let them kind of get on with it, frankly.

Baroness Greengross

Thank you very much, Simon. Dan, you’ve already had an advertisement for the Isle of Wight, but tell us your points.
The Isle of Wight Experience

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

I. Introduction

Thank you. I’m Dr Dan Harwood, Clinical Director for Mental Health Services on the Isle of Wight and also a full-time consultant psychiatrist working within the memory service on the island. I just want to highlight three ideas to improve quality and reduce cost based on some of the things that are going on on the island, but also, I’m sure, in many other parts of the county, and two challenges which I think are essential to be addressed if we are really going to improve the quality of care for people with dementia in this country. Many of the points have been made before, so I will try and keep it brief.

II. Opportunities to Improve Quality and Reduce Cost

1. Reduce the Number of Hospital Beds

There is too much emphasis on hospital care in the NHS, full stop. Hospitals are bad for people with dementia for all sorts of reasons which I don’t need to go into, so how are we going to address this problem and what are we doing about it? Well, on the Isle of Wight what we’re trying to do is reduce the number of beds in our inpatient unit for acute care for dementia, but also providing something different: using the money released we’re providing an inreach service to residential homes to support residents in crisis and help them see through their crisis to prevent an admission to hospital, and also a 24-hour helpline based on that inpatient unit so that staff who are expert in managing behavioural problems can be the first port of call for a care home having a problem with a patient avoiding – preventing unnecessary admissions.

2. Improve Care Pathway for Surgical Patients

The second bit of work we’re doing is in the general hospital working with anaesthetic and surgical colleagues to try and improve the care pathway of people with dementia who are going to have surgery. This work, I have to say, is in its early stages and we’re very lucky to have an anaesthetist with a special interest in this area. But what we’re trying to do is get people with dementia picked up before they have the surgery, then they have targeted interventions, including the special use of special anaesthetic agents which might be less toxic, improved analgesia and improved discharge planning. So the planning for someone’s admission and surgery starts before they’ve even come into the hospital at the pre-assessment clinic or in the GP’s surgery.

3. Effective Running of Day Services

The third point is about our community day service, which picks up nicely on this issue of cognitive stimulation therapy. 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.

III. Challenges

1. Integrated Working

Two challenges then to end with. Firstly, about integrated working. It’s my very strong belief as a clinician that the only way you provide decent care to patients is in a proper multidisciplinary integrated team and I mean a team including doctors, nurses, but also workers from the local authority, care managers, social workers, occupational therapists and so on – a proper multidisciplinary integrated team. The problem is the financial constraints. 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.

2. GP Commissioning

Lastly, a point about GP commissioning – really important. GPs are going to be in charge of commissioning, of deciding what services they want in parts of the country – all around the country and we’ve got a way to go in educating GPs about dementia and we must continue that work and continue it all the way through as GPs are commissioning services. Because unless they understand it, they’re going to commission the wrong services and there’s many GPs out there who don’t believe in early diagnosis and who don’t refer people early enough.

A lot of people talked about staff training and specialist services being involved in training and building up the expertise of domiciliary carers, of residential homes, of voluntary groups, etc, etc. That’s brilliant, but you have to think in a world of GP commissioning are the GPs going to commission us to do that training or are they going to be just interested in ‘No, we want you to see patients and prescribe drugs and do that’, because if people are going to do that training they have to be paid for it.

Baroness Greengross

Thank you, Dan. I think everyone would get in a little boat and go to the Isle of Wight if they could, and you’ve even got one MP who managed that. Thank you.

Leon, from Nightingale, I think when everybody was talking about small is beautiful you were always proving that big can be better. So we’re pleased to hear from you.
Oral Evidence from Care Home Provider

Leon Smith
Chief Executive, Nightingale House Care Home

I. Introduction

My name is Leon Smith. I run a very large care home situated in Clapham for older members of the Jewish community. We are looking after 200 people, some two-thirds of whom we believe have dementia at some and I believe that that two-thirds percentage is probably fairly representative of the care home sector at large. The main reason that people tend to come into residential care today tends to be because of dementia, because people simply can’t be supported any longer at home.

I’m looking at this through the perspective of a care home provider, so I’m seeing it through a slightly different prism and I think the work which you’re doing also needs to be set against the context of the Dilnot report, because a lot of the money that is being spent in the UK, a huge proportion of the money, is being spent by local authorities and, to a lesser extent, primary care trusts on commissioning care. A lot of money is being wasted. We have a very, very opaque and complex funding system, as we all know, and, hopefully, Dilnot is going to address that and, hopefully, the government is going to grasp the nettle and do something about it once and for all. And there are several points that I would like to make specifically in relation to funding and I’ll try and be as quick as I possibly can.

II. Funding Issues

1. People Divesting Assets

One of them is that people are becoming more and more savvy as to how the system works. People are proactively divesting themselves of their assets in order that when the time comes local authorities will be responsible for the care of their parents and not the individuals themselves.

2. Means Test for Families

The other thing which, in my opinion and some people consider this a little controversial, is that at the present time the means test which is carried out by local authorities is based on the applicant, on the older person themselves. I believe that that means test should be extended to the family, to the next of kin. We have many people in this country who are being supported at great expense by the council tax payer when the children are in a very, very good position themselves to try and support those people.

3. Third Party Contributions

Another area where I’m hoping that Dilnot – and I do realise I’m not talking to the Dilnot Commission, but I feel that all of these issues are relevant – another area where I feel that there is room for change is in the whole question of third party contributions. There are people out
there who would be prepared to make third party contributions towards the cost of care, which is being made difficult by some local authorities who play the game of pretending that the money which they are paying to care homes for the care of older people is actually covering the whole cost when clearly it isn’t.

4.  Respite Care

I would like to – although I don’t have any scientific evidence, I would like to say that in my opinion respite care is extremely important. It’s not only a question of giving a break to the carer; it is, in my opinion, enhancing the quality of life for a shortened period for the client themselves.

5.  Night Care

I also think that we should be looking not only at day care, but at night care. I’ve recently been looking at some models in Holland where night care is quite widespread and, again, the advantages of good day care and good night care clearly are that it prolongs the date when people need to go into institutionalised care.

6.  Mandatory Training

I personally believe, as a care home provider, that dementia care training should be mandatory in care homes in the same way that manual handling training is mandatory. And training can have so many side effects as well. 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.

Baroness Greengross

Thank you very much. We turn now to Graham, Graham Stokes at BUPA, a huge provider. Now, I’ve got a feeling the proportion of people in BUPA homes with dementia is much higher than Martin estimated. Is that right?

Oral Evidence from a Large Provider

Dr Graham Stokes

Director, Dementia Care, Dementia Care Service, BUPA

I.  Introduction

That’s right. Graham Stokes, Director of Dementia Care for BUPA, previously in the NHS where I was a consultant heading up neuropsychology services in an NHS foundation trust.
BUPA has 213 specialist dementia care units and approximately 66% of all people in our care homes, even if we’re not talking about the specialist units, have some severity of dementia.

II. Case Identification

What I’d like to do is to take us back to the point that Baroness Browning made and which was picked up by Karen Taylor. For me, this starts with the impoverished levels of case identification. When the national dementia strategy was announced two years ago, whilst there is great variability across the country, approximately 39% of people are identified, in the past two years that’s been uplifted to 43% and I think a very pertinent point was made – why is this so? And we can point to the fact that GPs seem more inclined now to see the value, but I think what we have to address is some immense structural issues as to why we don’t case identify. Because if we don’t case identify, then in essence 60% of people are drifting towards crisis, unknown to services.

III. Structural Issues

There’s a mythology around the average age to dement is 78. It’s expected that if you’re old you become absent minded, so no alarm bells are rung within families or within general practitioners.

It’s also the case that most people with dementia are comorbid. Twenty-nine percent of all people aged 85 with cancer, respiratory disease and heart disease are living with Alzheimer’s disease as well and GPs are making some very difficult priority decisions as to what conditions they should treat.

It’s the isolation that comes from advanced old age. The majority of people with dementia are elderly women who are living alone, who are not going to be able to go out to clinics to be assessed.

There is therapeutic nihilism. Many GPs still do not believe there is real benefit from an early diagnosis, but there’s also immense mistrust and I think that mistrust has to be addressed as well.

For many people who are diagnosed, especially if they’re diagnosed early – so they fall into that 40% - the extent of their care plan is little more than a discharge letter saying ‘thank you very much for referring, we have identified the person has dementia’, but secondary services shelter under the word ‘complex’ – if a person’s needs aren’t complex then they will not get involved. For ‘complex’ just read ‘crisis’. And so what we see is people with dementia either not known to services, drifting towards crisis or people who were actually diagnosed also drifting towards crisis. There’s a paper that’ll be coming out this month that looked at 34 people who were diagnosed in the memory assessment clinic. After being diagnosed with dementia they were discharged back to the care of their GP. We were interested to see what happened 18 months later, so when those 34 people were reviewed 18 months later one-third of those people living with dementia needed prompt referral to social services because their needs were becoming so great and 20% of family carers were clinically distressed because they felt they had been abandoned over the previous 18 months.

When you look at what those crises are that these two groups of people are drifting towards, they are minor medical problems. The datasets clearly reveal that when a person with dementia goes into a general hospital you’re looking at the consequences of falls, which are fractures and open wounds; you’re looking at urinary tract infections, carer distress, safety risks, and you could...
question whether people with that minor severity of medical need require admission to a general hospital.

When you look at the costs and the clinical outcomes, the costs are great, the clinical outcomes are poor and you could then start to say is it not possible then to use care homes in a far better way than they’re being utilised today? High specification care homes are staffed by skilled nurses. What they need is the support of their general practitioners, defined care pathways and any of those conditions could be met in a care home, step down care, intermediate care or whatever term we wish to use.

I will just use one example to conclude with. A urinary tract infection, payment by results tariff is £4,000. That is the average cost for the care of a urinary tract infection, £4,000. The average cost of a nursing home bed is £800. You can see a person would have to be in a care home for approaching five weeks before it would become more expensive to deliver the care in the care home as it did in the general hospital. One could anticipate that you could deliver a far better clinical outcome, but also a better quality of life outcome. General hospitals aren’t geared up to care for aged people let alone people who are aged and living with dementia. Quite understandably, on busy general hospital wards a person with dementia is seen as getting in the way. It’s one of the reasons why antipsychotics are prescribed to the extent that they are. In care homes, those nurses wish to work with aged people; you can see them as specialists in aged people and, as a consequence, you could argue their quality of life would be improved, because they would not be seen as getting in the way, because the raison d’être for those care homes is to care for those people who are disabled by infirmity or disease when they’re aged.

IV. Conclusion

So I think when we start looking at saving money and improving clinical outcomes there’s the beginnings, the question and the issue of case identification, the absence of care management following the diagnosis, so people are discharged prematurely. And then when those two sets of people are drifting towards their crises it’s general hospitals where you see the crises surfacing, without any creativity, because there’s no great evidence at all that commissioners are actually working with care homes to look at co-producing alternatives to general hospital admission.

Baroness Greengross

Thank you very much, all our witnesses. We have half an hour for questions.

Questions and Answers

Stephen Lloyd

Thank you very much. My name’s Stephen Lloyd; I’m the MP for Eastbourne. I’m going to concentrate on Graham. Nice to see you again. I saw you in Eastbourne only a few weeks ago and, forgive me, Sally, but possibly a little bit if Leon wants to come in as well, because it’s certainly on the day care side.

One of the things that came up clearly from the evidence and also what a number of people have said is the value of good respite care, both from the carer’s perspective, but if it’s good respite care,
from the suffer as well. Where I’m struggling a bit with the modelling, because I’ve got a number of day care, respite care establishments in Eastbourne and I know there are plenty around the country, the struggle is the local authority clearly has budgetary issues and wants to pay a minimum per day. For a lot of care homes that aren’t like Nightingale or BUPA, specifically designed for people with dementia, they are just care homes, but it’s quite clear a significant percentage of people in those care homes have dementia, the service is absolutely rubbish. But to try and persuade them to slice the margins so that a percentage of their people were sent to good day care dementia respite homes would be very, very challenging. So I suppose the question is how on earth can we square the financial circle when the numbers are so tight for local authorities and likely to get worse? And, secondly, how on earth do we persuade your run of the mill care home that is full of people with various degrees of dementia to actually take a cut from their own margins to allow some of their patients out into decent dementia day care centres? Any ideas?

Graham Stokes

Yes, or maybe I’ll just start and then we’ll pass it across, shall we? As has already been said that there needs to be an integrated whole system approach, 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 where the money would be better spent. You could see that money being utilised far better in step down care arrangements. I used the term ‘high specification care homes’. Not all care homes can deliver the quality of medical care and support that’s required if there are going to be step down arrangements, but it is achievable. It’s not achievable across the board. Please correct me if I’m wrong, Leon. I believe that both the Nightingale and BUPA are working with Bradford University to train our staff. Bradford University, probably the foremost university when it comes to delivering dementia care training and if you don’t have those staff trained to work effectively, efficiently and sensitively with the person who’s living with dementia I think it’s just a lot of empty words. How you persuade across the board that quality of training I’m not sure. I think you could argue there could be a Kitemark that would say ‘this home has achieved these standards in these areas’. We have CQC that should be doing along those lines already. I’m not quite so sure whether the CQC is actually drilling down what good quality care looks like to establish some Kitemark facility.

Leon Smith

So, what we’re talking about with the Centre of Dementia at Bradford is moving to very much the person-centred model of care rather than a task-orientated model of care. 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.

The other thing is that I think I accept because I'm running a charity, that there is also a societal responsibility here and, in my particular case where local authority commissioning payments don’t cover the costs, we recognise that certain amounts have to be raised from voluntary donations.

Simon Williams

Very briefly, you asked what persuades social services commissioners to invest in day care and also the question or not to disinvest. I’d probably say probably two things. One would be flexibility. That I think we’re most likely to keep investing in day care that we’re convinced offer truly flexible packages for carers and we would say some are much better than others at doing that.
And we’re specially conscious of things like lack of sleep for carers, for example, is probably the single biggest factor that actually leads people to stop caring, so we have to ask ourselves how does day care exactly help with that. It’s not a trivial point, but you just need to say how flexible is it?

Then the second issue, which I think has already been picked up, is: is it skilled and does it actually enable the person with dementia to retain as much cognitive function and independence as possible and is that transferrable in any way back into a home situation?

David Blunkett

I want to raise with Simon Williams the issue that was uppermost in our minds back in the 1970s when I was both Chair of social services in my city and the local authority lead nationally. We had joint funding in those days, the invention of Barbara Castle, but we’ve now got the top-sliced billion for adult care and we have the potential of using the health and well-being boards for prevention and early intervention. How do you see this working out in terms of dementia, because it’s right on the edge of the responsibilities? We’ve talked about commissioners; what about the mutual working of the local authority and the health providers, because that’s what it will be now, alongside the commissioning process?

Simon Williams

What you’re saying is how can we use what shared funding there is. Certainly 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. So we absolutely believe that that is an opportunity.

Health and well-being boards, certainly I’ve been saying there are lots of shadow health and well-being boards at the moment. I think a number of them want to ground their effort into something that’s really going to make a difference. I know my local cabinet member is certainly saying that this is not just a talking shop, how are we going to make a difference? I can’t think of a better example than dementia for a health and well-being board to get stuck into really, because it’s got everything. It’s got all the issues about how you look at needs, how you get health and social care to work together. So certainly we’re strongly encouraging that to be a priority, an early priority for those boards.

Hazel Blears

My question is for Dan primarily, although Simon might want to say something. And I’m just very, very worried about the GP commissioning role, because it’s been hard enough to get primary care trusts to be able to broaden their commissioning practice into some things which are not traditional health care and I worry about a medical model which is about prescribing and medical care, when in fact many of the things that work for people with dementia are not necessarily a medical model, they’re a social model about the quality of your relationship, your interaction, the things that Leon and Graham were talking about, about training and the way in which you treat people. And I would just like your view really. This is pushing on so fast and the pace is so great I’m not confident at all, personally. I have great GP consortia in my city, but I’m still not confident.
that they will get it in terms of what really works for dementia and it’s broader than a medical model.

Dan Harwood

I’d agree it’s a bit of an unknown, isn’t it? But I think there is a concern around that GPs don’t fully appreciate the evidence around that, social, psychological, educational interventions can have a real, positive benefit in terms of health outcomes for patients and carers with dementia and they don’t appreciate that, so they tend to focus very much on medicines. So the referrals I get is ‘Can you see this person for their anti-dementia drug?’ It’s not ‘Can you see them with a view to post-diagnostic counselling and support of carers and all the rest of it?’ But I think we mustn’t be negative. 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.

Gavin Barwell

My question is also, I think, primarily to Dan and it’s linked with Hazel’s question, although whether or not we were going down the GP commissioning route, clearly a number of you have a concern about the number of GPs who believe in early diagnosis and several of you referred to the need for GP education. How can that best be taken forward? What can best be done to get those numbers even higher than they are?

Dan Harwood

Well, on a very simple, pragmatic level, the data exists out there in terms of the practices about the referral rates from different practices, about which practices are putting people on the dementia case register and which aren’t, and about the rates of prescribing certain drugs; for example, antipsychotic drugs. And that can give you very useful data locally that you can use and that’s what we’re trying to use. There are clearly some practices that are excellent and there are also some practices that hardly seem to refer anybody. So it’s got to be done at a local level, hasn’t it, really? Mass education programmes don’t tend to work very well, in my view, in this area, because the ones who are going to be reached by that have been reached by it. And you put on an education training for GPs and it’s all the good ones who come along. So I don’t want to see you lot because you know it already. It’s the ones who are not coming. It’s the ones who are not coming. So we’ve got to target the ones who aren’t coming and you’ve got to tread gently and be careful, because you can’t go in and start badgering people, but you do need to go in, work with GPs, talk to them informally and use the competition. Doctors love competitions, don’t they, so if you can show that actually they’re the lowest practice in the county in terms of referral or the lowest rates of diagnosis, you can use that to your advantage and say, ‘Why do you think that is? Is it something to do with your demographics? Is it to do with your practice? How can we help you do better, really?’

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.
I don’t want to pessimistic about it, because the evidence is that GPs are getting better and I guess it’s a bit like the whole issue that cancer was 30 years ago, isn’t it, when people never even said the word and people didn’t talk about the diagnosis. Now we talk very openly about it. GPs are happy to talk using that word in front of patients and so are hospital consultants. So we’ve got to keep the pressure up and we’ll get there, I think.

Simon Williams

I think the other thing that pushes GPs’ buttons along with the evidence base is actually things that they see make a difference in their own surgery and their own clinical working lives. They’re not very interested in great documents and strategies; don’t have time to read them. So I think there are things we can do from social care to assist with that if we look at some of the better information and advice that they’re now seeking to make available. We absolutely see surgeries as a place to centre those systems so that GPs find it much easier to actually find their way to the right bit of information for a patient. There’s very good evidence where you have integrated multidisciplinary teams based around clusters of practices that actually that also makes a big difference. So I would add that along with the evidence base, but it’s got to find things that an average GP really sees makes a difference in their everyday working life.

Baroness Greengross

Well, I hope the Royal College will make this a priority too, because they need different training if GPs are to do this. It’s a new job, isn’t it?

Angela, you wanted to say something.

Baroness Browning

Thank you, yes. Again, to Dr Harwood. I wear another hat. I’m Vice President of the National Autistic Society and for years in the world of autism we had a huge problem with GPs. Many denied the condition existed at all, others thought it was something rather quirky that children would grow out of - all this sort of thing. One of the approaches we used was not actually to ask a GP to make a diagnosis. In fact, even today I wouldn’t expect a GP to diagnose autism, but I would expect a GP to recognise the signals and make an appropriate referral. And I just wonder if we take the pressure off them a bit, not expecting them to diagnose in the surgery in a 10-15 minute interview, but to be alert enough to know when to make the appropriate referral. And I have a member of my family who I’m a bit worried about whose memory is not good and I certainly wouldn’t expect the GP to suggest they went for drug treatment unless – they’re certainly not expressing challenging behaviour, but they’re memory’s not good and I’ve suggested to this relative that they go to the GP and say, ‘Can you refer me to a memory clinic locally?’ Because surely if we have those sorts of resources that’s the way the GP perhaps can become more engaged rather than having to take that very difficult decision in 15 minutes.

Dan Harwood

I agree with you entirely and I wouldn’t expect GPs to make a diagnosis at this stage in the game. Maybe a few years down the line, but not at this stage in the game, so if I gave that impression I didn’t mean to. It is about GPs recognising possible symptoms and referring and the golden rule is we keep trying to get across ‘if in doubt, refer’.
We get very, very few false positives coming into our service, so very rarely do I see someone and say, ‘Well, there’s nothing wrong with you’ and that makes me think, well, there’s a lot of people out there who we should be seeing. So GPs are not over-referring the worried well or people with nothing wrong with them. Their referrals are very appropriate and we just need to – I would rather see, actually, a few of the worried well, because it would make me think we were not missing people.

And to do an assessment – this point’s been made again, but I’ll make it again – doing an assessment early, early on and then, just to pick up on Graham’s point, 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 help lines 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.

David Blunkett

Sally, can I just say I’m married to a GP and all the pressures are to avoid referral. That’s where the pressures are going to be from now on.

Baroness Greengross

Graham, you wanted to come in. Can you take on board what David just said?

Graham Stokes

Yes, I’m just picking up on what Dan is saying that we mustn’t get overly preoccupied with diagnosis, because that is only the start. There is little merit in diagnosing if it doesn’t lead to anything and the latest data shows that survival times with dementia are increasing. A person who’s diagnosed with dementia in their 60s should expect to live for 11 years after diagnosis, so what is happening in those 11 years? And, as it stands at the moment, the answer is very little and until we actually say the reason for diagnosis will lead on to the support of a person and then increasingly the support of the family, I think you can understand why many GPs are saying, ‘Well, this could be opening Pandora’s Box. The person is diagnosed, is acknowledged as a clinical issue, but I’m left with nothing then to offer until the needs of that person and their family are deemed as complex’ – euphemism for ‘crisis’ – ‘and then the secondary services will step in at huge cost’. It’s whether you can invest to save and it’s whether – what authority will first invest to save by the delivery of managed care.

Baroness Greengross

David, does that answer some of –
David Blunkett

Yes. Only by whom; it’s the crucial element that has just been touched on, but it’s who does that?

Graham Stokes

Yes.

Baroness Greengross

Absolutely. Leon, did you want to come back on that?

Leon Smith

Only to just make a statement, which is that in my care home I have a very unusual GP arrangement whereby we have our own Nightingale registered medical practice. What that means is that although the GPs working as part of that Nightingale practice are also local GPs, they are working on a very, very regular basis with our clients and service users and so they are exposed on a daily basis to dementia and they’re learning along with everybody else. So I just think that that is a very good model.

Baroness Greengross

It is indeed.

Baroness Blood

I think we’ve got to be very careful that even though I agree that the GP is the first person you have contact with, I agree with Angela, I mean we’ve got to be very careful we don’t let the GPs down. Let me give you an example. Five or six years ago, I had a skin condition and I went to my own doctor. No problem. Went to see her a second time. No problem. It continued to get worse and I went back a third time and it was a locum doctor and she said, ‘I know nothing about skin, I’m going to refer you to the skin department’. I had cancer behind my eye. Now, if it hadn’t been picked up, I’d have lost my eye. So I think we’ve got to be very careful that we’re not laying it just at somebody’s door to do this.

Dan Harwood

Can I come back on that?

Baroness Greengross

Yes, please do, Dan.

Dan Harwood

Just to say there’s a theme coming out here, isn’t there, that it’s not just about diagnosis, it’s linking that diagnosis very clearly to appropriate treatment and a package of care. And it’s just to say that there’s an initiative that some of you may be aware of. The Royal College of Psychiatrists now
have what they call their ‘Memory Services National Accreditation Programme’ and we’ve recently been accredited and are awaiting our results. But that very clearly stipulates the good care pathway for dementia care, including diagnosis, but also including information given to carers, post-diagnostic counselling and support, day services, and you’re rated on all these sorts of areas. So it’s a good thing I think. We’re being encouraged, aren’t we, providers, to link up to these national clinical networks and accreditation programmes and this, I think, is a good one for memory services and it’s one where service users and carers’ input is paramount and you have to collect a large amount of data from those groups as part of your accreditation. So that’s one way, it’s by no means the only way, of trying to drive up standards across the nation’s memory service providers.

Hazel Blears

I wanted to ask Simon. We’ve all talked about integrated services and systemic change and all of that. Is there any hard incentive that you would think would help, particularly at a time of budget cuts, for people really to concentrate their minds on breaking down those barriers, in terms of a financial incentive or...?

Simon Williams

I think the incentives have always been there. The key issue ultimately is probably the most opportunity to unlock money is that you have 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, and that’s what is the issue. I heard earlier about joint finance back in the 1970s and the 1980s; well, that was one way of doing it and that was a way of pump priming new services.

Hazel Blears

And presumably they’ve done it in Lincolnshire because they’re forward-looking and progressive.

Simon Williams

Yes, essentially. I would –

David Blunkett

Which has come as a revelation, by the way.

Karen Taylor

The incentive there though was better quality care for the patient and the fact that they weren’t getting the quality of care that they needed in the hospital and all parties could see that there was better care could be provided elsewhere. So it’s about local partnerships, it’s about coproduction, cooperation.

Simon Williams

We look at QIPPS and all this stuff and it doesn’t always seem terribly focused from our perspective as social care. 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 a lot of the problems are that you don’t always get that focus; people are just looking at trying to do too many things in our experience. Actually, 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.

David Blunkett

Presumably, Sally, – if Dan would comment on this, I’d be grateful – you’re actually improving the quality of care in hospital for other patients as well, because I’ve had at least two relatives recently who’ve been in hospital where there’s been severe dementia on the ward, which has been very badly handled and it’s detrimental to the care of other patients.

Dan Harwood

I think we’ve got to address the fact that actually acute hospital admissions have changed dramatically. When I was a house officer and a senior house officer back in the late 1980s, early 1990s, the wards were full of people with really severe medical problems – epilepsy, asthma, heart attacks, severe heart failure. You go onto a medical ward now, it’s full of people with dementia and complex needs, because we’ve – that’s for two reasons: a) we’re actually better at preventing some of those crises, which is good; we’re better at preventing crises in asthma and heart attacks and so on. But b) the population’s aged, the incidence of dementia has risen, so more of those people come into hospital. So we’ve got to fundamentally change the way that we operate hospital care, haven’t we, and have – almost the specialty now needs to be the young people with an acute problem and the fact that geriatric medicine being a sub-speciality, well, that seems very outdated. Geriatric medicine is what medicine is now.

Baroness Browning

I just want to make a point about trauma wards, because this is where I’ve personally observed some most horrendous practice and it isn’t just about dementia. We’ve talked about the fractured neck of femur; elderly people go in with a fracture of one sort or another and underlying health conditions are totally ignored, whether it’s Parkinson’s, dementia, I’ve even witnessed somebody slip into a diabetic coma on a trauma ward. Now, it does seem to me that because it’s always bad on trauma wards and they’re trying to get people in and out as fast as possible, when they’ve got elderly people, it isn’t just dementia. I just really don’t understand why somebody doesn’t just do something about this. I mean it is quite appalling when you witness it firsthand.

Graham Stokes

I think that was the point I was trying to communicate. The majority of people who are in general hospitals with dementia are not there because of their dementia. They’re there for a co-existing or coincidental medical condition, which could be a fracture following a fall or an open wound following a fall and that’s the focus of attention.
Baroness Browning

Yes.

Graham Stokes

The dementia is seen as a hindrance. It is not seen as another example of care that is required. So as soon as that reason for admission has been addressed a discharge is required, but then the dementia steps in and it’s just seen as another inconvenience. So the question has to be why was this person not supported prior to this relatively minor health incident and could it not have been the case that if they did require medical care they could go somewhere other than a busy general hospital, a trauma unit or whatever else it might be. And that also includes end of life. I’m not trying here to be an advocate for care homes. End of life care can be practised very poorly in care homes and people are going into hospital to die. Nobody should go into hospital to die. No person themselves or their families would wish that to happen. But unfortunately what tends to happen in care homes, not only is there very little evidence of co-production, there’s very little evidence of engagement and a lot of evidence of abandonment. It’s this sense of you’re in a care home, there are nurses there, we will address the attention for those people who live in their own homes, and so, as a consequence, you actually see a reduction in the quality of medical support for people who are aged and dementing who go into care homes.

Baroness Greengross

Well, can I thank you, all six of our witnesses, because I don’t know about everybody else who’s here, but I’ve learned an enormous amount and I’m really very grateful, but also, just personally, but also I think colleagues form the Alzheimer’s Society will probably agree with me that this evidence has given us so much to work on. And I hope I’m speaking for all officers and members of the All-Party Group when I thank you very sincerely for helping us in what I truly believe is an extremely important issue and to find solutions, one way or another, which will benefit hundreds, indeed thousands, of people. So thank you very much indeed not only for what you said, but for giving us a lot of the basic evidence and information from which we can build the evidence that the Group needs if it’s to produce a really effective report which the Government and, indeed, the opposition parties, I’m sure there’ll be a consensus on an issue like this, that needs to be an absolute priority for the future. So thank you very much indeed and thanks to everybody else who’s come and listened.

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