



All-Party
Parliamentary Group
on Dementia

Building on the National Dementia Strategy:

Change, progress and priorities

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FOREWORD



In March 2014, we saw the National Dementia Strategy for England (NDSE) come to an end, while the Prime Minister's challenge on dementia is due to finish in May 2015. The Challenge has provided a momentum to the issues surrounding dementia, ensuring it is now a public policy priority. Given this increased focus on dementia, the Officers of the APPG felt this year was a good opportunity to revisit one of our previous inquiries, 'A missed opportunity? Inquiry into the funding of the National Dementia Strategy'. Published in 2010, this report made a number of recommendations about how the NDSE should be prioritised and taken forward. Four years later, this is an opportune time to reflect on our report and assess the progress made.

From all the key areas of improvement needed to best support people affected by dementia, we have picked three particularly important ones from our 2010 report, and consulted with experts from across the dementia community. In each of the three areas, we set out to establish what has changed since 2010, what progress has been made and to identify priorities for the future. The three areas we reviewed were:

- 1 Diagnosis and post-diagnosis support:** Our previous report suggested that the NDSE should invest in areas of urgent need. It is clear that the support a person receives at diagnosis and post-diagnosis is in need of urgent attention.
- 2 Commissioning:** In 2010 we recommended that PCTs should commission services based on evidence about their local health population.
- 3 Workforce:** We called for people with dementia to be cared for by an informed and effective workforce, a goal echoed in the Prime Minister's challenge.

This report contains a number of recommendations, which we hope health and social care policy-makers will carefully consider. The government, with support from all political parties, should be commended for maintaining its relentless focus on dementia in this parliament. However, there is no room for complacency. My fellow Officers and I hope that this short report will act as a positive contribution to the debate over what should follow the NDSE and the Prime Minister's challenge on dementia. There is still much more to do to improve the lives of people with dementia. We would like to see a redoubling of efforts by decision-makers in 2015 and beyond.

As health policy is devolved across the UK, this report focuses mainly on the English health and social care system. However, we believe that the recommendations are pertinent across all four nations.

I would like to thank the Vice-chairs and Officers of the APPG on Dementia for their hard work and commitment. Thanks also to Alzheimer's Society for providing the secretariat to the Group.

With best wishes,

Baroness Sally Greengross OBE
Chair, APPG on Dementia



1 SUPPORT FOR PEOPLE WITH DEMENTIA FOLLOWING DIAGNOSIS

In the APPG's 2010 report, 'A missed opportunity', we said we wanted to see more money being invested in urgent areas such as diagnosis and post-diagnosis services. The importance of this was further underlined in our 2012 report, 'Unlocking diagnosis', which highlighted the need to increase diagnosis rates of dementia and reported that good support for people following a diagnosis can lead to an increase in diagnosis rates.

Since 2010, diagnosis has been prioritised by NHS England in its refreshed mandate, with an ambition to increase the diagnosis of those with dementia to two-thirds by 2015, combined with appropriate post-diagnosis support. There have been many improvements in the care and support of people with dementia across the country. However, it is unacceptable that this remains so piecemeal and that many are not yet able to access improved support.

In our discussions with providers and commissioners of dementia services, we found examples of people with dementia, who received good-quality support, information and advice after their diagnosis. Good post-diagnosis support helps an individual to come to terms with their condition, plan for the future and enjoy life while they are still able to do so. It is our view that too many people with dementia are not getting the support they need following a diagnosis. We were also made aware of some of the challenges of implementing good post-diagnosis support. It is from these discussions that we make the following recommendations.

Recommendation 1: Clinical commissioning groups (CCGs) and local authorities must prioritise post-diagnostic support for people affected by dementia. This includes personalised advice, information and support, and ensuring that people with dementia know what to expect following a diagnosis.

It is clear that there is agreement within the dementia community that post-diagnostic support must be a priority. However, this sense of urgency has yet to filter down to CCGs and local authority level, and we want to see this happen as soon as possible. Through our discussions, it has become apparent that successful models share common features: strong leadership, a clear local dementia strategy and partnership working with voluntary and community organisations.

We could see the benefits that people with dementia gain from knowing what support to expect following a diagnosis. As Graham Browne, who lives with dementia, said:

'It would have been great to know that there was a person I could turn to, to point me in the right direction.'

We would like to see every person with dementia and their carers receiving the same level of support, according to their own needs, wherever they live in the country. We believe this is their right. As the rights of individuals are emphasised in the Care Act, we believe this could be used as an opportunity for health and care professionals to clearly explain to people with dementia what support they will get following diagnosis.

The issue of crisis prevention was also raised by many of the people we spoke to. Services need to be strengthened with additional funding and must support people with dementia and their carers to live independently in their own homes for as long as they are able and wish to. Services such as dementia cafés, peer support groups, carers support and befriending services are essential to reduce isolation and maintain wellbeing, but any support must suit the needs and wishes of individuals, as well as of their carers who may have their own health needs.

Recommendation 2: CCGs and local authorities must look to the Better Care Fund as an opportunity to integrate services in order to improve outcomes for people with dementia, and recognise that supporting people with dementia has benefits for other service users in their area.

From our discussions, it has become clear that people with dementia have the most to gain from integrated health and social care services. However, the current system does not favour any person with dementia. It is fragmented and difficult to get timely, co-ordinated care and support. At no point should a person with dementia or their carer be left without any support. As we discovered in our APPG 2012 inquiry, 'Unlocking diagnosis', it is challenging to increase diagnosis rates without the provision of the necessary post-diagnostic support.

NHS England has also given equal priority to diagnosis and post-diagnosis support, showing how closely the two are linked. Local authorities and CCGs can now use money from the Better Care Fund to commission diagnosis and support services together. We also want to see improved communication and data sharing between health and social care commissioners so that people with dementia experience a smooth transition between services. The role of Dementia Lead, which we will discuss later in this report, would be instrumental in ensuring that effective, joined-up working between health and social care, and people with dementia takes place and is maintained.

We see an important role for Dementia Advisers – or care coordinators – to guide people with dementia through the complex health and care services they may use. The Department of Health's commissioned audit of Dementia Adviser services shows that people with dementia often live better with the condition when supported by a Dementia Adviser. Integration of health and social care services is being actively pursued by commissioners in Kent as they work collaboratively to deliver joined-up services. We think that GPs also have a role to play; the General Medical Services contract change for 2014/15 means that patients over 75 should have a named clinician who will help identify the needs of people in that age group, including those with dementia. For people with dementia under 75, and more generally, GPs should be supported by and have regular access to colleagues with specialist knowledge of dementia, as well as information and support from voluntary sector groups and organisations.

Above all, we strongly believe that if integrated services work for people with dementia, they will benefit all people who use those services.

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2 COMMISSIONING HIGH-QUALITY DEMENTIA SERVICES

In 2010 we recommended that PCTs should use evidence of the needs of people in their area to inform their commissioning decisions. Since then, the NHS has undergone radical changes with regards to how funding is allocated and to the structures around the commissioning and provision of care. Major reform of the social care system has just passed through parliament. Throughout our inquiry, the issue of funding and increased financial pressures was expressed. It is unavoidable to take the view that this is having an impact on the quality of dementia services.

Commissioners of dementia services have witnessed great changes and now have to adjust to new ways of working, which includes joint working with health and wellbeing boards and closer links to public health in order to determine local need, and around prevention.

In our review, the APPG heard from a number of experts in the field of dementia services, from commissioners to service providers, who outlined some of the challenges they now face. We concluded that the following must be prioritised by commissioners of dementia services.

Recommendation 1: Every CCG and local authority should appoint a Dementia Lead with specific responsibility to ensure high-quality dementia services.

If we are expecting commissioners to prioritise dementia services, we believe it is important that they are able to seek guidance from strong leadership. Currently, there are no obligations on CCGs to have a Dementia Lead, although we are pleased that many CCGs already employ them. However, where they are in place, their roles vary widely. We believe Dementia Leads should have knowledge of the numbers and needs of people affected by dementia as well as local voluntary organisations and service providers that work with people affected by dementia. We think they should be the leading authority on dementia for commissioners to turn to.

Although we are not recommending that every CCG adopts the same specification for the role, the potential benefits of a Dementia Lead who demonstrates strong leadership are clear. Dementia Leads, working with the health and wellbeing board, could hold commissioners to account through the reviewing and monitoring of commissioning decisions, while their ability to facilitate joint working opportunities could be instrumental in the development of effective integrated care.



Dementia Leads could encourage commissioners to take advantage of the Better Care Fund and integrate services. We believe that people with dementia have the most to gain from integrated health and social care. However, commissioners must also take into account the links between housing, leisure and transport services. Working with commissioners, and health and wellbeing boards, Dementia Leads would be ideally placed to ensure that dementia is fully represented in the development of health and wellbeing strategies and subsequent commissioning plans. NICE published a guide called 'Commissioning health and social care for people with dementia' in 2013, which states that working together encourages integration. This might require commissioners to think creatively and consider how to make all their services accessible to people with dementia. The Dementia Lead would be the person who ensures this happens at a local level.

For Dementia Leads to be effective they must be granted the time and resources to provide that level of leadership and influence across organisations. Without Dementia Leads in place to provide leadership, influence and coordination, CCGs risk not being able to work effectively with other key stakeholders to commission the quality of service that people in their local populations need. We want Dementia Leads to have adequate resources and time to work in partnership with their CCG, local authority, service providers and voluntary organisations.

Recommendation 2: The Department of Health should establish a clear measure for quality of life for people with dementia, to be included in the Adult Social Care Outcomes Framework (ASCOF) from 2015/16.

There is currently no mechanism available to check that services are helping people with dementia to live well. We believe that local authority commissioners should provide services that prevent people with dementia from needing more intensive care in hospital or in care homes. The establishment of dementia-friendly communities will help to tackle wider issues around social isolation and inclusion, which many people with dementia experience.

Commissioners have told us that as diagnosis rates increase, there will be greater pressure on community services. We believe that people with dementia should not be admitted to hospital or go into a care home as a result of a lack of community services. The anticipation of pressures on services means that it is more important than ever to make sure services are supporting people with dementia to live independently. A new measure for quality of life included in the 2015/16 ASCOF would be a good way for commissioners to collect evidence to support their commissioning decisions. The new measure will allow us to see where in England people are living well with dementia and where this is not the case.

‘We believe that local authority commissioners should provide services that prevent people with dementia from needing more intensive care in hospital or in care homes. The establishment of dementia-friendly communities will help to tackle wider issues around social isolation and inclusion, which many people with dementia experience’

Recommendation 3: When planning and commissioning services, CCGs and local authorities, should:

- use evidence
 - assess local dementia needs
 - engage with people affected by dementia and use their personal stories
 - share data effectively and safely
 - consider dementia services in applications for the Better Care Fund.
-

We know that commissioners should base their commissioning decisions on evidence of need. However, there is a danger that this could become a box-ticking exercise. Commissioners should proactively seek available local data, such as the number of people with a diagnosis of dementia, as well as using personal stories from people with dementia that reflect local need. This can be done by seeking the expertise of local groups, organisations and service providers with support from a Dementia Lead. Our APPG 2013 inquiry, 'Dementia does not discriminate', found that people with dementia from black, Asian and minority ethnic communities can be socially isolated. Here, Dementia Leads could act as a link between local organisations, using their knowledge of the people they work with and commissioners, to ensure the needs of all people with dementia are met.

We also believe that people with dementia and their carers must be an integral part of the commissioning process. The Health and Social Care Act and NHS England both state that commissioners have a duty to engage with the public and patients. This must move away from being tokenistic to being integral and thoughtful. Commissioners must meaningfully engage and involve people with dementia and their carers, listening to each individual experience and ensuring their commissioning decisions are informed by the views of many people living with the condition. Involvement of people with dementia and their carers has to be representative and inclusive of harder to reach communities. Local Healthwatch, voluntary sector support groups and organisations such as Alzheimer's Society can play an integral part in helping to achieve this.

All commissioners we spoke to saw data sharing as an important part of the commissioning process. The 2013 report, 'Integrated care and support: Our shared commitment from the National Collaboration for Integrated Care and Support' (of which the Local Government Association is a member), identified data sharing as key to enable commissioners to target resources in order to suit the needs of their local population. This highlights the importance of collaborative working, with individuals and organisations sharing their knowledge and expertise in order to plan and deliver the very best, integrated services for people with dementia. We recommend that commissioners take advantage of the Better Care Fund to encourage collaborative working across health and social care.

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3 DEVELOPING A SKILLED AND EFFECTIVE WORKFORCE

This year's programme of engagement for the APPG has recognised some major challenges for the dementia community. One such challenge is how to ensure that the dementia workforce has the right skills and experience to deliver high-quality personalised care. We know that dementia is prevalent in hospitals and care homes, and two-thirds of people with dementia live in the community, so all people working in the health and social care system must be appropriately trained to work with people with dementia.

This issue is not new. In 2010 we recommended that people with dementia should be supported by a skilled and effective workforce. Yet reports, such as the 2013 Care Quality Commission (CQC) State of Care, say that people with dementia still do not always have enough support to live independently at home, are often admitted to hospital in an emergency or go into a care home earlier than they would like.

There have been some improvements thanks to work undertaken by Health Education England, Skills for Care and Dementia Friends, but the experts in dementia care who shared their views with the APPG said they still face huge challenges in developing a skilled workforce. From our discussions, we have prioritised the following areas.

Recommendation 1: There is a need for a major culture shift to improve the status and morale, both perceived and experienced, in care work to ensure it is an attractive and fulfilling career choice.

We believe that the care workforce carries out hugely important work; caring for older or disabled people should be recognised across society. However, many of those who work in the sector report that their work is seen as low status and accompanied by low pay. As we found in our 2009 APPG inquiry, 'Prepared to care', this is a major barrier to workforce development as it creates low morale and motivation. Care roles are often low-paid and therefore, staff may lack motivation to improve their skills and gain qualifications. This in turn leads to a high rate of staff turnover, which is linked to an increased risk of mortality, as reported in a 2014 study for the International Longevity Centre, called 'The future care workforce'.

A culture shift is needed. The quality of care can only be improved by tackling the ingrained culture within care work. This will take time to infiltrate through society, but as expressed by Skills for Care, service providers and training organisations should lead the way. Training should start at management level and must be personalised to suit the needs of each service provider. We also feel that managers can create a culture of openness and honesty by having the opportunity to engage in peer support and learning through each other's experiences. Training programmes, such as those offered by the Association for Dementia Studies, have a powerful impact; the training initiates a culture shift at management level, followed by practitioners who are dementia specialists and finally, front line care workers. Health Education England told us they are now looking to implement this model of training. It is important that training in dementia is consistent across health and social care and that there is consistency in its accreditation. This will also give commissioners confidence in the training that they purchase.

In the longer term, we feel that the government holds the responsibility to promote health and care work as an attractive career choice, encourage ambitious and qualified individuals to pursue such a career and reward those in the profession suitably.

Recommendation 2: Local authorities and CCGs must commission services that provide as much for a good quality of service, as for cost-effectiveness.

Commissioners should choose services based on quality and value for money rather than simply on price. According to a BBC Freedom of Information request, 17 out of 152 local authorities chose the price of services over quality. We recognise the huge financial pressures that local authorities are under, particularly in light of the services they are trying to commission, and that an increase in funding is needed. However, this pressure must not compromise the quality of services.

We are aware that short home care visits are still standard practice in some parts of the country. Short visits do not allow for person-centred care and leave people with dementia feeling anxious and bereft. They also offer very little job satisfaction to home care workers. In October 2013, Leonard Cheshire Disability, supported by Alzheimer's Society, highlighted the plight of local authorities commissioning 15-minute visits to people living in their own homes. We condemn the practice of 15-minute home care visits. We hope that the Care Act will address this issue and that good-quality, personalised care at home will support people with dementia so they can remain independent in their own homes for longer.

The UK Home Care Association estimates that the minimum price for home care services should be £15.19 per hour to allow care workers to earn National Minimum Wage and for service providers to deliver sustainable home care services. As well as encouraging a shift in culture, we see the Better Care Fund as an opportunity for health and social care services to work together and to use funds innovatively without neglecting quality. We want to see an increase in investment in workforce development to ensure we retain staff with the right skills in health and social care.

‘We recognise the huge financial pressures that local authorities are under, particularly in light of the services they are trying to commission, and that an increase in funding is needed. However, this pressure must not compromise the quality of services’

Recommendation 3: The government should establish a commission on workforce development, responsible for developing recommendations in order to ensure that people with dementia are supported by a skilled and effective workforce across health and social care.

An ageing population means that many older people are living with multiple conditions. It is clear to us that every person working in health and social care will have to support a person with dementia at some time in their career. Our discussions revealed that there are many questions around this issue that still need answers. For example, we can see that there is a skills gap and want to know how to resolve this. Other questions posed in our discussions focused on the need for minimum standards in training and who would ensure that these standards are met.

A commission on workforce development would be of huge benefit to people with dementia, their families and carers. The commission could examine these issues in more detail and make recommendations for the development of a skilled and effective workforce.

CONCLUSION

The APPG recommends a new, long-term dementia strategy, which incorporates our recommendations set out in this report, and involves people with dementia. This will be fundamental to the future of dementia care.

Five years on from the launch of the first ever National Dementia Strategy, the APPG on Dementia saw 2014 as an excellent opportunity to revisit our 2010 inquiry, 'A misspent opportunity'. Given that so much has changed since this report was published and that the National Dementia Strategy has now come to an end, we have taken the opportunity to look forward and examine what needs to happen for people with dementia in the future.

Following discussions and engagement events with commissioners, providers, experts in the voluntary and private sector, and of course people with dementia and their families it is clear to us that the government must commit to a new long-term strategy for dementia. Such a strategy should be bold and ambitious to be a worthy successor to the NDSE and the Prime Minister's challenge on dementia.

In this review, we focused our attention on three important areas: diagnosis and post-diagnostic support; commissioning dementia services; and developing a skilled workforce. We found common themes running through all our discussions and our recommendations are based around these.

Strong leadership

Dementia needs strong leadership from government, from local authorities and CCGs, and from service providers, to ensure it is a priority in every service.

Integrated health and social care services

People with dementia have the most to gain from integrated services and now is the best time to start putting this into action. We want to see all commissioners using the opportunity that the Better Care Fund offers to promote more integration across health and social care, which needs to be extended beyond the current financial limitations of the fund.

Engaging and involving people with dementia

People with dementia and their carers should have a say on any decisions that could affect them. Wherever possible, people with dementia should play an integral part in commissioning, training and providing support to other people with dementia.

Finally, we recognise that there are many other issues that require attention, which will significantly improve the lives of people with dementia and their families, but which we haven't covered in this report. These include investment in research as well as making progress towards the creation of communities that are more dementia-friendly. Our primary aim for this report is to identify some priority areas for government and to urge it to commit to a long-term successor to the NDSE and Prime Minister's challenge.

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APPENDIX

Evidence-gathering sessions

The APPG held three roundtable events in January and February 2014 where we heard evidence from experts within health and social care. The APPG would like to thank the following individuals and organisations for their contributions to the roundtable discussions.

Name	Organisation
Baroness Greengross OBE	APPG on Dementia
Rt Hon David Blunkett MP	APPG on Dementia
Tracey Crouch MP	APPG on Dementia
Rt Hon Paul Burstow MP	APPG on Dementia
Michelle Barber	Lambeth CCG
Sarah Bickerstaffe	Institute of Public Policy Research
Margaret Bracey	Sussex Partnership NHS Foundation Trust
Graham Browne	Living with dementia
David Corcoran	Department of Health
James Cross	Skills for Care
Josie Dixon	Personal Social Services Research Unit
Lizzie Dowd	Royal College of Nursing
Anna Dowrick	Alzheimer's Society
Gillian Drummond	Greater Manchester West Mental Health NHS
Matthew Egan	Unison
Jake Eliot	National Housing Federation
Cllr Gillian Ford	Local Government Association
Bill Gibbons	Alzheimer's Society
Susan Grose	Lewisham CCG and London Borough of Lewisham
Patrick Hall	Social Care Institute for Excellence
Rob Henchy	Peterborough City Council
Sophie Hodge	Memory Services National Accreditation Programme

Jo James	University College London Partners
Dr Ann Johnson MBE	Living with dementia
Robert Jones	West Norfolk CCG
Kelly Kaye	London Borough of Redbridge
Dame Betty Kershaw	Support for Ann Johnson
Ellis Layward	North Norfolk CCG
Vicki Leah	University College London Hospitals
Julian Lloyd	Alzheimer's Society
Paul Mancey	Orchard Care
George McNamara	Alzheimer's Society
Ann Moulder	Alzheimer's Society
Joanna Newton	Alzheimer's Society
Eve Oldham	London Borough of Hackney
Catherine Pascoe	Hampshire County Council
Lewis Pickett	Care Quality Commission
Dr Mareeni Raymond	City and Hackney CCG
Steven Reading	Alzheimer's Society
Karla Richards	Lewisham CCG
Professor David Sallah	Health Education England
Lara Sanolo	King's Fund
Anna Shears	Department of Health
Becky Sidwell	Department of Health
Kathryn Smith	Alzheimer's Society
Duncan Stephenson	Care Quality Commission
Rachel Thompson	Royal College of Nursing
Elisa Vaughan	Alzheimer's Society
Sue Wardle	London Borough of Redbridge
Peter Watson	Carer of a person with dementia
Duncan White	UK Homecare Association
Dan Windross	London Borough of Islington

The All-Party Parliamentary Group (APPG) on Dementia is a group of cross-party parliamentarians with an interest in dementia. It was created to build support for issues surrounding dementia and encourage it to become a publicly stated health and social care priority in order to meet one of the greatest challenges presented by our ageing population.

The APPG prides itself on remaining at the forefront of debates on the future of dementia care and services. Over the past six years, we have run annual parliamentary inquiries into the key issues affecting people with dementia, their families and carers. This year, our report looks back at a previous inquiry. We reflect on the progress made since that inquiry and make recommendations for the future.

Acknowledgements

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