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All-Party
Parliamentary Group
on Dementia



Dementia rarely travels alone:

Living with dementia
and other conditions

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FOREWORD



The challenge of dementia and our national response to it has reached a critical point.

Over the last five years its profile has risen to unprecedented levels. The government's commitment has seen much needed improvements in raising public awareness, improving diagnosis rates, and creating dementia-friendly communities.

However, our political leaders now have a decision to make. The attention that dementia merits is finally being realised, thanks to the work of both this and the previous government. Can we find the time, resources and focus to continue what they started?

The number of people living with dementia is increasing. Research shows that 7 in 10 people living with dementia are also living with another medical condition. They are also trying to find their way through a health and social care system that does not have the capacity to manage the complexity of their conditions and their day-to-day lives.

‘Research shows that 7 in 10 people living with dementia are also living with another medical condition’

People living with dementia frequently fall through the gaps in the system. It is a problem that improved public awareness or a better diagnosis will not solve. The management of long-term conditions is the key challenge facing the health and social care system, and its solution is far from easy. We need to see profound changes to the way we view the patient as well as the overall system.

This year the APPG sought evidence to bring about this change. It investigated the problems faced by people living with dementia and one or more health conditions and outlines these in detail in this report.

In writing this, we acknowledge that dementia has been the primary focus of the current government's manifesto pledge on health, and we commend them for it. This report, produced by a working group of parliamentarians across all parties, is our offer to government and the NHS to ensure that the emphasis on dementia continues.

We are committed to working together to see these recommendations enacted, and in doing so improve the lives of people managing both dementia and one or more comorbid conditions.

Sally Greengross

Debbie Abrahams

**Co-chairs of the APPG on Dementia,
Baroness Sally Greengross OBE and Debbie Abrahams MP**



SECTION 1: DEMENTIA AND COMORBIDITIES

1.1 Living with dementia and other health conditions

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. It is caused when the brain is damaged by diseases, such as Alzheimer's disease, or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.

‘There are 850,000 people in the UK living with dementia, 42,000 of whom are under the age of 65’

There are 850,000 people in the UK living with dementia, 42,000 of whom are under the age of 65. Many people with dementia also live with one or more other health conditions. Studies have shown that:

- 41 per cent have high blood pressure
- 32 per cent have depression
- 27 per cent have heart disease
- 18 per cent have had a stroke or transient ischemic attack (mini stroke)
- 13 per cent have diabetes (Barnett et al, 2012).

The relationship between dementia and comorbidities can be complex and variable: high blood pressure and diabetes can increase someone's risk of dementia; having a stroke can cause dementia; and depression can be a consequence of it. Other comorbidities that may be present are coincidental, eg arthritis.

The severity of someone's dementia can have consequences on their ability to manage their other conditions. For example, someone managing diabetes has to carry out self-testing and administer insulin at certain times of the day. Because of the dementia, their ability to carry out this task will deteriorate as their memory and cognition worsens, with responsibility eventually falling to a carer. Mismanagement of a health condition can lead to someone falling seriously ill, resulting in an emergency admission to hospital. It can also mean that the progression of the condition is quicker compared to if they didn't have dementia.

The prevalence of many of these conditions increases with age. People are living longer and the population is ageing, meaning more people are developing dementia and comorbidities. How these people are treated, cared for and supported becomes increasingly complicated as people's needs compound and become more complex. One of the biggest challenges facing society today is building a health and social care system that can provide holistic, person-centred care and support for this growing body of people. To address this issue, the APPG has focused its first inquiry of the new parliament on dementia and co-morbidities.

1.2 Collecting the evidence

In September 2015, the APPG put out a call for evidence to voluntary organisations, the Royal Colleges, academics, practitioners, service providers, commissioners and people affected by dementia.

They asked targeted questions around the barriers and solutions to supporting people with dementia living with multiple long-term conditions. We received around 30 submissions that comprehensively cover the views of all of the aforementioned groups. Alzheimer's Society also held two focus groups, on behalf of the APPG, with people with dementia and carers to find out their experiences of living with dementia and other conditions.

The officers of the APPG held two oral evidence sessions in November and December 2015, which looked at the issues around self-management and changes to health and social care systems. Details of the expert witnesses can be found in the Appendix section to this report.

1.3 What we heard

Perspective from a person with dementia

The inquiry heard from a range of people affected by dementia that living with comorbidities as well as dementia makes their lives increasingly difficult. With dementia affecting memory, language, problem solving, communication and physical symptoms (ie weight loss, muscle weakness), these symptoms can prevent someone from self-managing the symptoms and treatment regimens associated with other conditions.

To add to this, the dementia itself will increase the risk of people receiving poor care for their other conditions.

According to the UK Faculty of Public Health at Royal Colleges of Physicians:

'People living with dementia and comorbidities are also less likely to receive the equivalent level of care for similar conditions than people living without dementia due to delays in the recognition of new or exacerbating symptoms' (Fox et al, 2014).

Terry Eccott, who was diagnosed with dementia in 2013, shared his story at the oral evidence sessions:

'Dementia is seen by almost everyone as just a memory problem, so it is not common knowledge that day-to-day tasks become more tiring – physically as well as mentally. Simple things like getting up in the morning or walking down the road shopping can seem like a mountain to climb. You become more and more fatigued to the point you're exhausted before you even start the day.

The brain starts to not send those important messages to the body to move, so it becomes harder; the muscles waste, you put on weight because you cannot exercise, which then becomes a vicious circle you cannot break. This breaks down the body's strength and immune system.

I have cardiac arrhythmia and angina which of course only worsens the condition as the blood flow alters and causes TIAs – transient ischaemic attacks, commonly known as mini-strokes. This then affects the dementia.

On top of that, the attitudes around you change, even with professionals. For example, a new doctor you've not seen before, or a nurse you have, start talking to you differently once you've been flagged on their notes as having dementia. They tend to start to ignore what you're saying and talk over you, and you seem to be a child again. This for me leads to frustration, but I bite my lip and say nothing because if you do, you are usually marked as an argumentative, aggressive dementia patient.'

Perspective from a carer

As dementia progresses, carers end up taking significant responsibility in supporting people with increasingly complex needs, doing everything from providing meals to administering medicine to co-ordinating someone's care. Their task is made more difficult because they often don't have enough information about the health conditions or how they interact or interrelate with one another. In addition, carers are not fully informed on how to manage these conditions collectively or where to turn for care and support. A lack of information and support often leads to carers taking on too much, burning out or feeling helpless to prevent crises that could have been averted with more professional help.

One carer told us:

'The carer, if the person is lucky enough to have one, has to take on the responsibility for managing all the conditions. So often when I take my husband to the GP or a hospital appointment, the doctor looks only at the specific condition being dealt with at that appointment. I have the responsibility of ensuring that the whole picture is looked at.'

Some people told us they were expected to attend over 20 different agencies, bodies and organisations to access the care and support they needed. This is a near impossible task for someone who is frail, elderly and has dementia, without considerable help. We heard that people routinely lost track of appointments or had to prioritise between them because they didn't have the capacity to attend each one. Many felt that healthcare professionals were not

helping them to plan or co-ordinate their care properly. Moreover, they felt that they had to repeat their story to each professional as no one had overall oversight of their health or care.

A co-ordinated approach

We also heard what a difference a co-ordinated approach can make. For example, Action on Hearing Loss expressed how communication difficulties caused by unaddressed hearing loss and/or dementia can lead to a lack of diagnosis, misdiagnosis and/or mismanagement of either or both conditions. However, proper management of both vastly improves outcomes.

'Evidence suggests that proper diagnosis and management of hearing loss, including provision of hearing aids, reduce the risk and impact of dementia and some of the other associated comorbidities such as falls and depression' (Action on Hearing Loss).

In light of the evidence, it is clear there are several essential factors that will help people living with dementia and comorbidities. They include access to good quality information, a comprehensive care plan, regular multi-disciplinary assessment and reviews of care and support, and a care co-ordinator. These factors will help get them the integrated care and support they need from health and social care services and enable them to self-manage their conditions effectively. Whilst the importance of these components of personalised care is widely recognised in public policy (eg the Care Act) many people with dementia and comorbidities struggle to get them in practice.

Academics, voluntary organisations, health and care professionals and commissioners provided deeper insight into why the health and social care system struggles to provide person-centred care.

They told us that despite recent policy initiatives such as the NHS New Models of Care and the Better Care Fund (BCF) driving integration, the health and social care system is still struggling to come to terms with the challenges of delivering holistic treatment and support for the ever growing population with increasingly significant, complex, long-term needs, such as those with dementia and comorbidities. At the centre of the issues is that much of the health and social care system was set up to treat conditions in isolation rather than care for someone holistically.

The British Psychological Society said:

'Given the strong association between dementia and other health needs, statutory services should be organised to treat multi-morbidity as the norm rather than as an exception. However, all too often, services treat illnesses in isolation from one another. This treatment of disease within separate silos of specialisation is a barrier to diagnosis, management and support (reference from Barnett et al, 2012).'

The separate silos of specialisation that prevent effective diagnosis, management and support exist across the health and social care system in a multitude of ways. These include:

- commissioners lack the data on people with dementia and comorbidities that allows them to commission integrated, personalised services
- reviews of care for people with multiple morbidities in general practice often only consider one health condition
- clinicians lack guidance around how to prescribe medicine to people with multiple morbidities
- the Care Quality Commission, the health and adult social care regulator, inspect individual providers rather than care pathways.

The financial implications of mismanagement are staggering. Research by the International Longevity Centre – UK (ILC) found that people with dementia are less likely to have cases of depression, diabetes or urinary tract infections diagnosed. Those that do get a diagnosis are less likely to receive the same help to manage and treat these comorbidities. This can lead to people's dementia progressing more quickly, which in turn leads to greater health and social care costs. The ILC – UK estimate the combined cost for mismanagement of dementia and these three conditions alone is at least £994.4 million annually (ILC – UK, 2016).



SECTION 2: RECOMMENDATIONS

2.1 What needs to change?

The complexity and scale of the health and social care system, the current budgetary constraints on the NHS and local government, and the individual and complex challenges people with dementia and comorbidities face mean there is no silver bullet to resolve these problems.

Recognising this challenging context and that numerous national, regional and local initiatives such as the NHS New Models of Care are already driving integration of services and developing better care, the following analysis and recommendations takes a pragmatic approach, identifying cross-cutting solutions that complement existing programmes of work to enable people with dementia and comorbidities to receive better quality, holistic care and support. They are grouped into the following themes:

- improved risk reduction
- GP-led holistic annual reviews
- new guidance for medication management
- better data for joint commissioning
- regulation of care pathways as well as providers.

2.2 Improved risk reduction

Despite dementia being the most feared health condition among people over the age of 50, the inquiry found a lack of awareness of the risk factors for developing dementia (YouGov: What the world thinks, 2012). The awareness of people affected by dementia was extremely variable in understanding the links between type 2 diabetes, heart disease, stroke and dementia. The same applied to people's understanding of the public health mantra 'what is good for your heart, is good for your head.'

Public Health England is working to ensure that people understand the risks of unhealthy lifestyle decisions by inviting everyone aged from 40 to 74 to have an NHS Health Check. Health checks enable people to understand how their lifestyle choices dictate their risk of developing health conditions, such as those listed above. From the age of 40, people who attend the check are given an overall score that tells them their risk of getting heart disease or stroke.

However, in spite of this, dementia lacks the precedence of other health conditions in the check. This is despite research showing that careful management of diet, exercise, sleep, smoking and alcohol intake from middle age is particularly important in decreasing someone's likelihood of developing dementia and related comorbidities.

It is only from the age of 65 that dementia is discussed as a mandatory part of the check. We commended Public Health England's announcement in March 2016 to enhance the dementia component of the check, and plans to pilot a dementia risk assessment tool across three small scale sites. However, hundreds of thousands of people under the age of 65 are still not being sufficiently encouraged to take action to reduce their risk of dementia before it's too late. To rectify this, Public Health England must ensure everyone receiving an NHS Health Check has their risk of dementia assessed and discussed appropriately, whatever their age.

Recommendation 1: Public Health England should mandate a dementia component in the NHS Health Check for people aged 40 to 65 years old to enable people of all ages to take action to reduce their risk of dementia.

2.3 GP-led holistic annual reviews

GPs' knowledge of common health conditions, their connection to the rest of the health and care system as well as their base in the community, makes them well placed to take a leading role in care planning and care co-ordination for people with dementia and comorbidities. However, there are a number of barriers to them doing this effectively.

The inquiry heard that when someone develops a long-term condition, such as diabetes or dementia, they are placed on a GP's register for that condition. If they have multiple conditions, they will be on each respective condition's register. GPs are required to routinely review each condition, and will call people in for separate reviews of each one. This is despite many of the reviews sharing similar elements eg taking someone's blood pressure or weight. The inquiry heard the story of a woman in a care home who received four letters inviting her to separate appointments for each of her conditions. It was not only a logistical nightmare for her and the care home, but also indicative of a lack of proper oversight of health and wellbeing and lack of care co-ordination.

Martin Green, Chief Executive of Care England, said:

'It must be remembered that people living with dementia and a range of other comorbidities do not have the energy, or indeed sometimes the knowledge, to constantly challenge the system and it should be the responsibility of central government to set out clearly its expectations of what people living with dementia and other comorbidities have a right to expect, and they should have a mechanism to call areas to account when this is not delivered to a level that is acceptable to the citizens who use services.'

The Quality Outcomes Framework (QOF), the payment mechanism that underpins GP practice, incentivises separate reviews. In place of separate reviews, people with dementia and comorbidities should have a minimum of one comprehensive, holistic review of their health per year. It should initially be led by a GP, and draw on other health and social care professionals as required. This should be reflected in an update of all aspects of a person's care plan, from medication to social care support. In a survey of 1,518 health professionals across the NHS (including GPs) regarding the need for a holistic, GP co-ordinated, annual review, 88 per cent agreed with this recommendation.

At the oral evidence session Professor Alan Sinclair, Director of the Foundation for Diabetes Research in Older People, said:

'We have the Quality Outcomes Framework, the voluntary incentives that GPs have to perform more assessments, review blood tests and so on. We have quite a lot of points awarded for good diabetes care and we have some points awarded for dementia, but the fact is they're not linked. They're totally separate. Nobody thinks to do the other. And so I think we have to relook at the QOF, because I think there's a great opportunity in primary care to start making a difference in that area.'

Changing the QOF was instrumental in improving diagnosis rates for people with dementia. If the Department of Health changes the framework to incentivise holistic annual reviews of people with dementia and comorbidities, it could have a similarly profound effect. It will help to ensure that people are receiving the holistic care and support they need and are able to self-manage their conditions effectively. GPs will also be enabled to spot any health issues far earlier. This could dramatically reduce the number of people with dementia who go on to reach crisis point before finding themselves admitted to hospital, at a great personal cost to themselves and a financial cost to the NHS.

Recommendation 2: The Quality Outcomes Framework should be revised by the relevant bodies to ensure people with dementia and comorbidities receive a minimum of one GP-led holistic review of their care and support per year.

2.4 New guidance for medication management

A key component of a person's annual review and care planning should be their medication. People with dementia and comorbidities often have to take a number of medications to treat different conditions.

Laura Marsh, the Commissioning Manager for Long Term Conditions at NHS Bath and North East Somerset, said:

'Patients with vascular dementia often have other cardiovascular diseases [...] the main difficulty is poor medication compliance because the person with dementia can forget to take their medications for other conditions. However, recurrent urinary tract infections are problematic as some people forget to eat and drink enough fluid – this is especially problematic if there is no carer who can help promptly.'

When medicines interact negatively, it can exacerbate someone's dementia or another health condition. For example, the inquiry heard from a man with dementia whose anticholinergic medication for his bladder problems made his dementia worse, making him confused, drowsy and more likely to fall. It was decided that this put him at a greater risk than not taking it at all and consequently he came off the medication.

Clinicians told us that they are routinely forced to make difficult decisions about medication for frail elderly people with multiple morbidities; something they currently do without comprehensive guidance. The more medication someone is taking, the more complicated the decision and the bigger potential risks of mismanagement. Clinicians also have to ensure someone is supported and able to take their treatment – something that can be more difficult as a consequence of someone's dementia.

We heard many stories demonstrating this challenge for both patients and clinicians, and this appears to be the norm. But we also heard a positive example where all medications were taken into account.

A person caring for her husband diagnosed with posterior cortical atrophy seven years ago responded to the inquiry:

'The treatment my husband received from a hospital geriatrician was excellent. She looked at the whole individual from top to toe – assessing the risks of each condition and which needed treatment and which could be managed by medication or simply left alone. This holistic view is very good for the patient and a huge relief for the carer.'

Community pharmacists can also play an important role. By checking that individuals are taking their medication, they can prevent duplicate prescriptions and manage interactions between medications. However, links between community pharmacists and GPs are weak in many areas.

The Royal Pharmaceutical Society is set to develop polypharmacy guidance for England. It is essential that this guidance addresses the complex needs of vulnerable elderly people living with dementia and common comorbidities, by engaging widely with clinicians, pharmacists, voluntary organisations and people affected by dementia and comorbidities. The guidance should strengthen partnerships between GPs and community pharmacists to ensure that pharmacists are involved in comprehensive reviews.

Recommendation 3: The Royal Pharmaceutical Society should develop new guidelines on polypharmacy for England that address how to treat people with dementia living with multiple long-term conditions.

2.5 Better data for joint commissioning

The APPG heard that health and social care services often treat conditions or illnesses in isolation from one another. As a result, people with dementia living with several long-term conditions experience disjointed care because the various medical professionals fail to communicate with each other. Without someone co-ordinating their care or mutually agreeing upon a care plan, people end up being stuck between health and social care services, with neither offering support. Stories of unnecessary emergency hospital admissions and carers experiencing crises when support has not come at the right time as a result were well-documented in the evidence.

In their submission, Parkinson's UK said barriers to integration included a lack of accurate registries of data about both patient needs and the overall population. In addition, it also lacks a system of coding that would enable a holistic, longitudinal view of a patient's use of health and care services. Although dementia is a health condition, the nature of the condition means that people with dementia need significant support from social care services. As dementia progresses, a person's needs will become more complex, especially if they are living with several long-term conditions. So it is clear that, as people with dementia will use services across health and social care, they have the most to gain from jointly commissioned and delivered health and social care services.

‘Although dementia is a health condition, the nature of the condition means that people with dementia need significant support from social care services. As dementia progresses, a person's needs will become more complex, especially if they are living with several long-term conditions.’

The NHS New Models of Care, Better Care Fund, Devolution deals and Integrated Personal Commissioning are exciting vehicles for health and social care commissioners. These programmes can help to jointly reconfigure care pathways to ensure people with dementia receive personalised, integrated care. Fundamental to this is the high quality data for commissioners regarding people with dementia and their comorbidities. Huge leaps have been made recently with the creation of the Dementia Intelligence Network, a data tool that combines all relevant dementia data sources and is searchable by locality. However, as this inquiry has found, comorbidities are common among people with dementia and need to be factored in to local service design. Public Health England needs to incorporate these data sources into the Dementia Intelligence Network so commissioners are truly able to commission joined-up services for people with complex needs.

Recommendation 4: Public Health England should include data on dementia and common comorbidities in the Dementia Intelligence Network to provide health and social care commissioners with the data to commission integrated care pathways.

2.6 Regulation of care pathways as well as providers

The Care Quality Commission (CQC) is the regulator for health and adult social care providers. They inspect providers to assess how safe, effective, caring, responsive, and well-led they are. This is important to ensure organisations are delivering good quality care, and improvements are made where required. However, the inquiry heard that current inspections tend to focus on specific settings, or thematic reviews that look at a particular condition in certain settings, rather than someone's experience across a complete care pathway.

With CQC consulting on their new five-year strategy, it's essential they look to develop methods to assess and inspect care pathways, including those delivered in the community. Multi-disciplinary assessments, reviews and care planning, and co-ordinated care delivery, are integral to someone with dementia and comorbidities receiving integrated, holistic, personalised support, and therefore should form key considerations of inspections. This would support CQC to further raise standards in care and support for people with dementia and comorbidities, particularly at the points where health and care services interact.

Recommendation 5: CQC inspection regimes should assess the quality of care pathways across health and social care settings alongside the performance of individual providers.



CONCLUSION



The inquiry into dementia and comorbidities has outlined the scale of difficulty faced by people living with dementia and other conditions and the huge financial costs of mismanagement. Despite considerable policy initiatives and programmes of work to deliver integrated care services and support, the health and social system all too often treats conditions in isolation so that people with dementia and other health conditions receive disjointed, substandard care and treatment, or receive little support at all.

However, there is much that can be done. We need more targeted awareness raising of the risk factors for dementia and comorbidities through a revamping of the NHS health check to include a dementia risk assessment component. This will enable people at risk of dementia and related comorbidities to take action before it's too late.

To ensure people have an integrated care plan and their care is properly co-ordinated, every individual living with dementia and comorbidities should have a minimum of one holistic review of their care and support per year. This should be led by a GP and draw on consultations from health and social care professionals as required. A revision to the Quality Outcomes Framework will ensure such reviews take place.

The management of medication for people with dementia and comorbidities is a significant issue for clinicians. With many treatments having adverse effects on other health conditions and a lack of guidance for clinicians on this issue, it is essential that the Royal Pharmaceutical Society develop guidance that addresses the needs of people with dementia and comorbidities as soon as possible.

The advent of the Dementia Intelligence Network has improved the data available for commissioners across the country. Data on common comorbidities must be added to the network so that joint commissioning of care pathways and packages of support can be delivered effectively for people with dementia and comorbidities across health and social care settings.

‘Without a radical change in focus and priority, we will consign many more thousands of people to substandard care and a poor quality of life, wasting hundreds of millions of pounds in the process. It is therefore essential that these recommendations are taken forward by decision makers.’

Finally, to consider the quality of care for someone with dementia and comorbidities, it's important that the Care Quality Commission looks beyond care in particular settings to inspect care pathways. This will enable them to better understand patient experience and help improve integration of services, ultimately better meeting the needs of people with dementia and comorbidities.

Managing multiple long-term conditions is the number one challenge for the health and social care services this century. Urgent action is needed if we are to see this group of people better supported and ensure an NHS that can not only survive, but is equipped to meet this challenge head-on and support people to live fulfilled lives.

Without a radical change in focus and priority, we will consign many more thousands of people to substandard care and a poor quality of life, wasting hundreds of millions of pounds in the process. It is therefore essential that these recommendations are taken forward by decision makers.

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APPENDIX

Officers of the APPG on Dementia

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Lord Warner

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Dr John Pugh MP

Dr James Davies MP

Jim Fitzpatrick MP

Oliver Colvile MP

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Oral evidence:

Below is a list of expert witnesses who gave evidence to the enquiry

Terry Eccott, living with dementia

Viccie Nelson, Programme Director, Homecare Vanguard, Sutton Clinical Commissioning Group

Duncan Burton, Director of Nursing & Patient Experience, Kingston Hospital NHS Foundation Trusts

Dawne Garrett, Professional Lead for Care of Older People, Royal College of Nursing

Dr John Holmes, Senior Lecturer in Liaison Psychiatry of Old Age, Leeds University

Barbara Jesson, Lead for Medicines Optimisation, Croydon Clinical Commissioning Group

Dr Frances Bunn, School of Health and Social Work, University of Hertfordshire

Professor Alan Sinclair, Director of the Foundation for Diabetes Research in Older People, Aston University

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Professor Yoon Loke, Older People's Medicine, University of East Anglia

Written evidence will be published at alzheimers.org.uk/appg

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 dementia as 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 seven years we have run annual parliamentary inquiries into the key issues affecting people with dementia, their families and carers.

This year, our report looks at the care and support people with dementia and other conditions receive.



Alzheimer's Society provide the secretariat for the APPG on Dementia

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The photographs in this report are for illustrative purposes only: the people appearing in the images are models, and do not suffer from dementia.

