

# Dementia and comorbidities

## Ensuring parity of care

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# Executive summary

This report demonstrates that there is a pressing need for action to improve how comorbid medical conditions are prevented, diagnosed, treated and managed for people with dementia in the UK. While dementia is often viewed as an isolated condition, we demonstrate that this patient group suffer from a high prevalence of comorbid medical conditions which frequently remain undiagnosed, and in many cases are preventable. People with dementia are also less likely to receive the same help to manage and treat their comorbidities than people without dementia. As a result of this lack of parity, this group suffer a faster decline in daily functioning, a reduced quality of life, and die earlier than people who have the same comorbidities, but do not have dementia.

More specifically this report finds that:

## *Increased risk of early mortality*

- In-patients with dementia are over three times more likely to die (18% of patients with dementia) during their first admission to hospital for an acute medical condition than those without dementia<sup>1</sup>.

## *Increased economic costs*

- Untreated comorbidities, by speeding up the cognitive decline of people with dementia, may be resulting in a significant financial loss for the health and social care systems - we have demonstrated a total net loss of approximately £377 million for people with dementia and diabetes, £115.7 million for people with dementia and UTIs, and £501.7 million for people with dementia and depression (see appendix 1).

## *Many comorbidities could be prevented*

- Four of the five most common comorbidities people with dementia are admitted to hospital for in the UK are preventable conditions - a fall, broken/fractured hip or hip replacement, urine infection and chest infection<sup>2</sup>.

## *People with dementia are less likely to receive help to manage and treat their comorbidities*

- In England, people with dementia are substantially less likely to receive age-related treatment to stop loss of vision<sup>3</sup>.

## *Comorbid conditions are often only being detected once the symptoms of the comorbidity have become severe*

- 42% of unplanned admissions to an acute hospital of people over 70 have dementia<sup>4</sup>.



**42%** of **unplanned admissions** to an acute hospital of people **over 70** have dementia<sup>4</sup>.

This report identifies six key areas which appear to be leading to the discrepancy in health outcomes for people with dementia and comorbidities:

- 1. Atypical symptoms.** People with dementia often present atypical symptoms which may lead to carers and medical professionals interpreting these problems as worsening dementia and neglecting other conditions as a potential cause.
- 2. Communication difficulties** between medical professionals/carers and people with dementia, and between medical professional themselves, leading to lower standards of care.
- 3. A failure by the health system to recognise the individual as a whole**, instead focussing on the person as a patient with a given diagnosis, leading to the optimisation of care for dementia while the individual continues to deteriorate because of poor management of a comorbid condition or vice versa.
- 4. A knowledge gap of hospital staff and carers** in caring for people with dementia and comorbidities.
- 5. Poor medication management** relating to how people with dementia's medications are prescribed, monitored, administered and/or dispensed.
- 6. A lack of support to aid self-management and poor monitoring of comorbidities** by health professionals.

However, the relevance of each of these areas varies depending upon the particular comorbidity being addressed. This report has investigated three conditions in the UK to identify the specific challenges and gaps in care for people with dementia, and has found:

#### *Depression*

- Antidepressants are often the first treatment for people with dementia and depression, however there is a lack of robust evidence for the use of antidepressants in dementia patients, with a recent NHS-funded evaluation finding that two commonly prescribed antidepressants had no effect compared with placebos on the depression of people with Alzheimer's disease<sup>5</sup>.
- Involving caregivers in care decisions helps to identify depression in dementia patients as they can help to get around the communication difficulties present. However, in 33% of care homes and 61% of hospitals, there are aspects of variable or poor care regarding how people, together with their families and carers, are being included in decisions about their care<sup>6</sup>.

#### *Diabetes and dementia*

- A UK study of hospital in-patients found far fewer people with dementia were diagnosed with type-2 diabetes than controls without dementia<sup>7</sup>, suggesting diabetes is currently underdiagnosed in this group.
- The NICE National clinical guideline for management in primary and secondary care of type 2 diabetes does not include any reference to dementia<sup>8</sup>, despite the high rate of dementia and diabetes comorbidity.

#### *Urinary tract infections and dementia*

- Urinary tract infections, along with pneumonia, have been found to be the principal cause of hospital admission (41.3%) of people with dementia<sup>9</sup>, despite both conditions being avoidable and easily managed with prompt access to medical care.
- The use of urinary catheters is more frequent amongst patients who are documented as having dementia<sup>10</sup>, suggesting that health care practitioners may be prioritising ease of management of patients over reducing their chance of contracting a UTI<sup>11</sup>.

We have set out seven recommendations which we believe will help to ensure parity of care for people with dementia and comorbidities:

1. The National Institute for Health and Care Excellence (NICE) must update its condition specific guidelines to take into account the needs of people with dementia in order to ensure this group receive the same level of care as the rest of the population.
2. Care homes should modify the care plans of residents with dementia to include checklists covering the symptoms of common comorbidities (such as UTIs) to help ensure early diagnosis and treatment.
3. Health professionals must involve people with dementia, their carers and families in every decision about their care to improve both the diagnosis and management of comorbidities.
4. Health Education England should consider broadening its tier one dementia awareness training to include how dementia may affect care for both short and long term conditions.
5. Health trusts should develop comprehensive catheter action plans, based around staff education and training, to reduce the incidence of UTIs in people with dementia through unnecessary catheter usage.
6. The Care Quality Commission (CQC) should consider making it mandatory for care homes to undertake annual check-ups for residents with dementia and diabetes where their blood glucose levels, cholesterol levels and vision are monitored.
7. Clinical Commissioning Groups (CCGs) should commission a wide range of psychological therapies at a suitable capacity to ensure that GPs are not reliant on drugs to treat depression in dementia patients.

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# Introduction

The UK's ageing population has helped lead to a huge increase in the number of people with dementia, and it is estimated that in 2015 there were more than 850,000 people living with the disease<sup>12</sup>, a number which is projected to increase by 40% over the next 12 years<sup>13</sup>. This growth is impacting on the lives of individuals, their families and caregivers. It is also leading to increasing recognition that health and care services need to adapt in order to provide high standards of care for this growing patient group. This has been highlighted in both national and local dementia strategies, as well as in the Prime Minister's challenge on dementia. However, while encouraging, many of these strategies have focussed on dementia in isolation, without any recognition that people with dementia suffer from a high prevalence of concurrent medical conditions known as comorbidities.

While comorbidities are often treatable and some may be reversible, the focus on dementia as a condition in isolation, both in public policy and in medical practice, risks comorbidities remaining undiagnosed, potentially reducing people's quality of life and leading to early mortality. It also risks people with dementia not receiving the appropriate treatment when they have been diagnosed, as dementia has the potential to complicate care for other conditions, as well as making management of those conditions more difficult.

Despite these potential risks, and the growing number of people with dementia, there is a scarcity of research into this area. This report sets out to help fill this gap by investigating the relationship between dementia and comorbid conditions, with a specific focus on the situation in the UK.

The first section looks at how a diagnosis of dementia can affect the prevention, diagnosis, treatment and management of comorbid conditions, highlighting the differences between people with dementia and the general population. As part of this we present new quantitative evidence investigating the link between untreated comorbidities in people with dementia and increased health and care costs.

The second section investigates why these differences are occurring, looking at physical and behavioural factors, the views and practices of medical professionals and carers, and the way in which health and social care services are set up.

The final section of the report looks at how having dementia may affect the prevention, diagnosis, treatment and management of specific comorbidities in the UK, focussing on depression, diabetes, and urinary tract infections, with illustrative 'good' care stories for each.

# Approach

This report is informed by a three stage systematic review of both academic and grey literature. The first stage of the review investigates broad questions around the relationship between dementia and comorbidities, and the differences in health outcomes for people with dementia in comparison to the general population. This stage was framed by a focus on:

- Comorbidity prevalence amongst people with dementia
- Prevalence of specific comorbidities
- The economic cost of comorbidities
- The relationship between a diagnosis of dementia and the prevention, diagnosis, treatment and management of comorbid conditions

As there is a scarcity of research into the relationship between dementia and comorbidities, the review concentrates as far as possible on evidence from the UK, but also includes international evidence to help elaborate on the UK findings, as well as the relationship between dementia and comorbidities more broadly.

In investigating the economic cost of comorbidities we also carried out quantitative analysis modelling how untreated comorbidities in people with dementia can increase costs by causing a deterioration in the dementia. This involved calculating the number of people likely to be affected by dementia and one of the following specific comorbidities: diabetes, urinary tract infections and depression. Because comorbidities are often underdiagnosed in dementia patients, we applied the same age specific prevalence rates as found in the general population. We then calculated how many of those affected by dementia and one comorbidity are likely to have mild, moderate or severe dementia by applying the prevalence rates by severity of the condition as given the ILC-UK's 'Preventing dementia: a provocation' report<sup>14</sup>. Finally, we calculated the difference in aggregate cost if all of the patients with dementia and a comorbidity get worse, i.e. shift from mild to moderate dementia, from moderate to severe and from severe to death. A more detailed methodology of the approach used can be found in appendix 1 of this report.

The second stage of the review builds upon the first by investigating why there are differences in healthcare outcomes for people with dementia. This was framed by a focus on:

- Physical factors
- Behavioural factors
- Views and practices of medical professionals
- Views and practices of carers
- Set-up of health and social care services

The third stage of the systematic review investigates how the findings of the first two stages relate to specific comorbidities in the UK, focussing on depression, diabetes and urinary tract infections. These conditions were selected so as to cover both physical and psychological conditions, conditions that are likely to arise both before and after the development of dementia, those which are highly prevalent amongst people with dementia, and those of which there is available UK evidence.



## **What are comorbidities?**

The concept and definition of comorbidity itself is complex. Comorbidity can be defined as two or more chronic conditions, or as the total burden of biological dysfunction<sup>15</sup>. Multimorbidity is a newer term which can also account for medications, lifestyle behaviours, disability, and socioeconomic stressors<sup>16</sup>. Regardless of the definition, the concept of comorbidity explicitly recognises the possibility of interactions and competing risks between conditions, meaning that comorbid conditions and their treatments can have effects greater than the sum of the individual conditions<sup>17</sup>.

# Dementia and comorbidities - why is this such an important issue?

## How prevalent is comorbidity amongst people with dementia...

Research has found that the prevalence of comorbid conditions in people with dementia is high<sup>18</sup>. For example, studies have estimated that 61% of people with Alzheimer's disease have three or more comorbid diagnoses<sup>19</sup>. As the severity of the dementia increases, so does the rate of comorbid conditions<sup>20</sup>. Dementia patients suffering from comorbid conditions are also highly prevalent in hospital settings. For example, approximately one in four acute hospital beds across England, Wales and Northern Ireland are occupied by people with dementia, with the primary cause of admission being a physical health issue<sup>21</sup>.

## ...and what comorbidities do people with dementia have?

There are common comorbidities amongst people with dementia. A Spanish study found that hypertension and diabetes were the comorbidities most frequently found in older people with dementia<sup>22</sup>. Although, the analysis revealed that both these conditions are common in older people in general the investigators also identified 12 conditions that appear to be "significantly associated" with dementia - Parkinson's disease, congestive heart failure, cerebrovascular disease, anemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, retinal disorders, prostatic hypertrophy, insomnia and anxiety/neurosis<sup>23</sup>. Other international studies have had similar results<sup>24 25</sup>.

For most of these comorbidities, a plausible pathophysiological explanation can be found. Some could be considered as risk factors (cerebrovascular disease), others as complications (skin ulcers), and others just as comorbidities (osteoporosis)<sup>26</sup>. However, while there is a common comorbidity profile of people with dementia, it is important to remember that there are a number of different dementias. Any common profile will inadvertently reflect the situation of people with Alzheimer's disease as this is by far and away the most common form of dementia. For example, patients with dementia with Lewy Bodies have been found to have a worse comorbidity profile, with a higher occurrence of depression, stroke and migraine, compared with patients with Alzheimer's disease<sup>27</sup>.

## Increased risk of early mortality and reduced quality of life

People with dementia and comorbidities suffer a faster decline in daily functioning, a reduced quality of life, and die earlier than people who have comorbidities, but do not have dementia. A UK study found that in-patients with dementia are over three times more likely to die (18% of patients with dementia) during their first admission to hospital for an acute medical condition than those without dementia<sup>28</sup>. Worryingly, this association remained significant after controlling for age and severity of acute physical illness, suggesting that people with dementia are not receiving the same level of care as older people without the disease.

The link between dementia, comorbidities and early mortality is corroborated by international research. For example, an American study found that over half of patients with moderately severe dementia admitted to hospital with hip fracture (55%) or pneumonia (53%) died within 6 months<sup>29</sup>. This is drastically greater than for patients without dementia (12% and 13% respectively)<sup>30</sup>. People with dementia and comorbidities also have a faster decline in their daily functioning than people with only dementia, being about one to two years ahead of the decline of dementia patients without any comorbidity<sup>31</sup>. Additionally, research has found that people with dementia who have comorbidities suffer a greater decrease in their quality of life than people who have the same number of comorbidities but do not have dementia<sup>32</sup>.

## The rising economic costs of people with dementia and comorbidities

Dementia has been predicted to cost the UK economy £26bn a year, with the current cost of dementia diagnosis and treatment to the NHS coming in at £4.3bn<sup>33</sup>. International research suggests that part of this cost could result from people with dementia and comorbidities not having their conditions appropriately managed, resulting in them accruing greater treatment costs than adults who do not have dementia but suffer from the same comorbid conditions. For example, an American study found that treating the comorbidities of people with dementia generates 34% greater healthcare costs than treating age-matched non-dementia cases<sup>34</sup>.

Another US study found that for the 10 most prevalent comorbidities in patients with Alzheimer's disease and related dementias (ADRD), adjusted costs were higher for dementia patients compared with control subjects with the same condition<sup>35</sup>. The comorbid diseases in question are those commonly targeted for disease management, indicating that the greater costs may be due to people with dementia receiving too little or inappropriate support to manage their comorbid illness<sup>36</sup>.

However, our own analysis suggests that undiagnosed or badly treated comorbidities are also increasing health and care costs in the UK by speeding up the cognitive decline of people with dementia (see appendix 1). As previously mentioned, the decline in daily functioning of people with dementia and comorbidities is approximately one to two years ahead of the decline of dementia patients without any comorbidity. This shift to more severe forms of dementia not only results in people's quality of life decreasing, but also results in their associated healthcare costs escalating earlier - for example a patient with mild dementia who costs £26,212 a year, who then develops moderate or severe dementia is likely to then cost between £39,294 and £41,187 a year.

Focussing on three conditions – diabetes, urinary tract infections (UTIs), and depression - we have found that untreated comorbidities in people with dementia may be increasing health and care costs significantly by causing a deterioration in the dementia. Assuming that cognitive function in patients with both dementia and a comorbidity declines 2 years faster than patients with dementia only, we estimate that there is currently a total net loss of approximately £377 million for people with dementia and diabetes, approximately £115.7 million for people with dementia and UTIs, and £501.7 million for people with dementia and depression (see appendix 1).

Significant savings could therefore be made to health and social care by developing policies and strategies that effectively address how to prevent, diagnose, treat and manage comorbid conditions in people with dementia. For example, putting systems in place which aid people with dementia to properly manage their diabetes should cost significantly less than treating them in an acute hospital ward. With the number of people with dementia in the UK predicted to increase from around 850,000 to 1,142,677 by 2025<sup>37</sup> it is vitally important that policy makers address this issue now to help offset the rising strain being put on health and social care services.

# Quality of care – the evidence

While comorbidities amongst people with dementia are common, the presence of dementia has the potential to complicate care for other conditions and make management of those conditions more difficult. For example, the inability of many people with dementia to adequately express their symptoms increases the risk of them not having their comorbidities diagnosed or adequately treated, not only reducing their quality of life, but also potentially leading to greater health care costs and early mortality.

This section looks at the available international evidence, with a particular focus on the UK, to highlight how a diagnosis of dementia may be affecting the prevention, diagnosis, treatment and management of comorbid conditions.

## Prevention

Many of the comorbidities that people with dementia suffer from are preventable. While the physical and psychological changes brought about by the disease do increase people's risk of certain preventable conditions (such as fractures resulting from falls) the high prevalence of these conditions in this group also suggests a failure in the care they are receiving. For example, in the UK, a survey by the Alzheimer's Society found that four of the five most common comorbidities that people with dementia were admitted to hospital for were preventable conditions - a fall, broken/fractured hip or hip replacement, urine infection and chest infection<sup>38</sup>.

An American study had similar results, finding that people with dementia entered hospital with a range of preventable conditions, of which pneumonia, urinary tract infection and congestive cardiac failure accounted for two-thirds; and dehydration and duodenal ulcer were the next most common<sup>39</sup>. Australian research found these issues continued into hospital care, with dementia patients more likely than non-dementia patients to develop potentially preventable comorbidities whilst in this setting<sup>40</sup>.

## Diagnosis

Detecting both the dementia and the comorbid condition is the first step in providing effective support for older people with dementia and comorbidities. However, dementia is currently underdiagnosed in the UK, while the international evidence suggests that patients with dementia are also more likely to have undiagnosed comorbid conditions. A Finnish study found that 66% of dementia patients had at least one undiagnosed disease compared to 48% of patients without dementia.<sup>41</sup> The study also found that patients with dementia were significantly more likely to have undiagnosed hypercholesterolaemia and undiagnosed hypothyroidism than people without dementia<sup>42</sup>. Another study, looking at the diagnosis rates of a range of conditions, found that people with dementia were less likely to be diagnosed with hypertension, joint arthrosis and loss of vision and hearing<sup>43</sup>. The authors highlighted that all four of these conditions are unlikely to be less prevalent in people with dementia, and were therefore being underdiagnosed<sup>44</sup>. If this weren't the case, their results suggest the implausible scenario that having dementia leads to better vision and hearing.

In the UK, evidence highlights that people with dementia and comorbid conditions are often only being detected once the symptoms of the comorbidity have become severe. For example, there is an extremely high rate of unplanned acute emergency medical admissions for this group- 42% of unplanned admissions to an acute hospital of people over 70 have dementia<sup>45</sup>.

## Management and treatment

People with dementia are less likely to receive the same help to manage and treat their comorbidities than people without dementia. For example, a UK study found that people with dementia in England may be substantially less likely to receive age-related macular degeneration treatment to stop loss of vision<sup>46</sup>. International evidence highlights that this lack of support can be found in a range of areas. Dementia reduces the likelihood that individuals with diabetes will receive recommended annual monitoring<sup>47</sup>; reduces the chance that people with Alzheimer's disease and atrial fibrillation will receive oral anticoagulants or antiplatelet agents<sup>48</sup>; and reduces their access to intravenous thrombolysis for stroke<sup>49</sup> and cataract surgery<sup>50</sup>.

Pain also appears to be poorly managed in people with dementia. An American study found that patients with advanced dementia and a hip fracture were prescribed only one-third of the analgesia compared with cognitively intact controls<sup>51</sup>. Untreated pain and discomfort both cause unnecessary suffering and behavioural problems for someone with dementia. The behavioural problems then have the potential to be misinterpreted and lead to the inappropriate use of psychiatric medications<sup>52</sup>.

These results suggest that the poor management and treatment of comorbidities is widespread, and this may be a significant factor in the increased risk of early mortality and reduced quality of life faced by people with dementia when diagnosed with the same comorbidity as non-dementia patients.

## End of life care

The above evidence suggests that people with dementia are receiving less help to treat and manage their conditions which is leading to poorer health outcomes. However, research also suggests that the terminal prognosis of late stage dementia, especially when combined with acute comorbidities, is not being taken into account by health professionals, leading to patients at the end of their life being subjected to unnecessary burdensome treatments and not receiving appropriate end of life care.

A UK study examining the case notes of patients aged 70 or over who died whilst an inpatient on an acute medical ward found that referral to end of life (palliative) care and the prescription of palliative medications was significantly less frequent in patients who were documented as having dementia<sup>53</sup>. American research supports this, finding that there were no significant differences in the number of burdensome, painful procedures received by end-stage dementia and cognitively intact patients, despite the increased risk of mortality suffered by the people with dementia<sup>54</sup>. Simultaneously, hip fracture patients with end-stage dementia received, on average, less than half the amount of pain relief compared with patients without dementia<sup>55</sup>.

# Underdiagnosis, poorer management and treatment – why is this occurring?

Dementia is a chronic, progressive, debilitating and ultimately fatal condition that affects every aspect of a patient's life; its consequences therefore need to be considered in every care and medical decision, including the treatment of comorbid illnesses<sup>56</sup>. However, the above evidence suggests that people with dementia are being underdiagnosed with comorbidities and, when diagnosed, receiving poorer management and treatment of these conditions.

Researchers have hypothesised that when a person is diagnosed with dementia, this could result in an altered approach to diagnosis and treatment of comorbid conditions partly as a result of the patients' altered help-seeking behaviour<sup>57</sup>. A model developed by Piette and Kerr<sup>58</sup> posits that conditions such as dementia, which are clinically dominant, are highly symptomatic, or involve treatment or self-management that is not harmonious with another condition, and so may dominate clinical encounters and shift attention away from care for the other condition.

## Atypical symptoms

Recognising and treating comorbid conditions in a person with dementia may be challenging because they present atypical symptoms. Changes in health status in people with more advanced dementia often present as increased confusion, falls, loss of appetite or dehydration. The relationship between these symptoms and the underlying cause may not be obvious. For example, research has found that patients with dementia were less likely to have traditional orthostatic hypotension symptoms like dizziness, and instead presented symptoms such as mental fluctuations, confusion, drowsiness, and slow falls<sup>59</sup>. This may lead to carers and medical professionals interpreting these problems as worsening dementia and neglecting other conditions as a potential cause. This can delay diagnosis and specific treatments that can improve patients' safety, daily function, and quality of life<sup>60</sup>.

## Communication difficulties

Evidence suggests that poor communication - between medical professionals/carers and people with dementia, and between medical professionals themselves – is leading to lower standards of care for people with dementia and comorbidities. A recent scoping study by University College London (UCL)<sup>61</sup> found that practitioners reported difficulties in communicating with people with dementia, and these difficulties were made worse by comorbidities involving the senses, such as hearing loss or sight loss<sup>62</sup>. The difficulty which people with more advanced forms of dementia find to communicate their symptoms and care wishes means that it is vital that their families and carers are involved in the decision making process. However, a report by the Care Quality Commission (CQC) found that in 33% of care homes and 61% of English hospitals surveyed, there were aspects of variable or poor care regarding the involvement of people or their families and carers in decisions about their care<sup>63</sup>.

Research has also found that the care of people with dementia and comorbidities is being affected by poor communication between medical professionals themselves. The scoping study<sup>64</sup> found evidence suggesting a lack of coordinated working between practitioners in different specialities<sup>65</sup>, while the report by CQC found 27% of care homes and 22% of hospitals had aspects of variable or poor care in how information was shared when people with dementia were moved between services<sup>66</sup>. This lack of communication is compounded by older adults with dementia being subject to more transitions in care, for example between care home and hospital settings<sup>67</sup>. Each transition presents a new risk for miscommunication, duplication of services, medical errors, and provision of care in conflict with the best interests of the person with dementia<sup>68</sup>.

## Failure to recognise the patient as a whole

People with dementia are being underdiagnosed with comorbidities and, when diagnosed, receiving poorer management and treatment of these conditions, in part because of a failure by the health system to recognise the individual as a whole and instead focussing on the person as a patient with a given diagnosis. Many clinicians are familiar with the gallows humour of the surgeon who reported “the operation was a success but the patient died,” but they would perhaps find this less amusing if it was changed to “the glucose was well-controlled but the older adult ended up in the intensive care unit on mechanical ventilation in a hypoglycaemic coma<sup>69</sup>”.

The optimisation of care for dementia while the individual continues to deteriorate because of poor management of a comorbid condition, or vice-versa, may be being exacerbated by medical guidelines often being condition specific and generally failing to take into account comorbidity or the needs of a person with dementia. For example, the NICE National clinical guideline for management in primary and secondary care of type 2 diabetes does not include any reference to patients with dementia<sup>70</sup>, despite people with type 2 diabetes being significantly more likely to develop the disease<sup>71</sup>. Additionally, NICE is currently developing a guideline for multimorbidities, however the current draft specifically states that it will not cover the management and organisation of care for people with dementia<sup>72</sup>.

## A knowledge gap of health professionals and carers

The knowledge gap of hospital staff and carers in caring for people with dementia has been widely documented, and may lead to poorer quality of care for people with dementia and comorbidities. The CQC report found that 27% of care homes and 56% of hospitals had aspects of variable or poor care regarding staff understanding and knowledge of dementia care<sup>73</sup>. It also found that 29% of care homes and 56% of hospitals had aspects of variable or poor care regarding how a person with dementia’s needs were assessed<sup>74</sup>.

“In all my years of training, I have never, ever, ever, been taught how to look after patients with dementia’ [hospital consultant physician]<sup>75</sup>”.

The UCL study<sup>76</sup> corroborated this, finding that a lack of appropriate knowledge and training about dementia was a significant barrier to individuals working in acute care hospitals, palliative care and diabetes<sup>77</sup>. It also found that medical professionals specialising in dementia lacked awareness about how to support people with dementia and comorbidities<sup>78</sup>.

## Poor medication management

Poor medication management may be contributing to people with dementia having worse health outcomes for their comorbidities, and may even result in additional comorbidities. As people age, they are far more likely to be prescribed more than one medication. For example, a study of 55 UK care homes found 256 residents were taking an average of eight medicines<sup>79</sup>.

Multiple medication usage amongst people with dementia and comorbidities is common as they are often taking medication both for the dementia itself and for the other conditions. For example, people with dementia and type 2 diabetes may be taking anti-diabetic, anti-hypertensive, anti-platelet and lipid lowering medications<sup>80</sup>, as well as a combination of acetylcholinesterase inhibitors, memantine hydrochloride and antipsychotics for their dementia<sup>81</sup>.

For someone coping with memory loss, it can be particularly difficult to manage multiple medications. People with dementia may simply forget to take their medications, causing them to skip doses, or equally if they can’t remember whether they took their medication, they might take it again, causing a drug overdose. This can have potentially disastrous consequences, leading to serious health complications or even death. For example, a Dutch study of 13,000

unplanned admissions found that impaired cognition was the main predictor of preventable medication-related admission to hospital<sup>82</sup>.

However, poor medication management is not constrained to the person with dementia. Research suggests that family carers of people with dementia often have difficulty managing the medication regime of the person with dementia and lack the knowledge to weigh up the risks and benefits of different drugs<sup>83</sup>. A UK based study found that carers reported difficulties in maintaining supplies of medication, ensuring adherence by the person with dementia to their medication regimen, and accessing health professionals<sup>84</sup>.

Medication management errors have also been found to be regularly committed by professional carers and medical professionals. For example, the UK care home study found 69.5% of residents had one or more medication error relating to how their medications were prescribed, monitored, administered and/or dispensed<sup>85</sup>. Contributing factors to these errors included doctors who were not accessible, did not know the residents and lacked information when prescribing; high workload, lack of medicines training and drug round interruptions; lack of team work among home, practice and pharmacy; inefficient ordering systems; inaccurate medicine records and prevalence of verbal communication; and difficult to fill medication administration systems<sup>86</sup>.

### **Drug interactions**

Polypharmacy, or the taking of multiple medications, can also lead to drug interactions which adversely affects the health of people with dementia. The likelihood of an adverse drug reaction rises sharply with the number of drugs and doses taken<sup>87</sup>, so the high number of medications often taken by people with dementia and comorbidities puts them at particular risk. For example, an extensive literature review found that many drugs used to treat physical health conditions may worsen the symptoms of dementia, either by negating the effects of cognitive enhancers or through direct adverse effects on cognition<sup>88</sup>. This risk may be being increased by medical professionals prescribing dementia medications which aren't necessary.

An American study of 5,406 nursing home residents with advanced dementia found that the majority were receiving at least one medication with questionable benefit<sup>89</sup>.

“In my clinical work I frequently meet older people who cannot tell me why they are taking certain medications, as well as individuals who have had medications prescribed for many years without a review<sup>90</sup>”.

### **A lack of support to aid self-management and poor monitoring of comorbidities**

People with dementia's ability to self-manage their comorbidities is often reduced due to the high levels of cognitive dysfunction associated with the disease. For example, a UK study looking at cognitive dysfunction in older subjects with diabetes mellitus found that subjects with low levels of cognitive function required significantly more assistance with personal care behaviour<sup>91</sup>. The level of self-management achievable varies between individuals, and changes over time as the dementia progresses.

Ongoing monitoring and modification of care goals and treatments by health professionals is therefore paramount to ensuring that a person with dementia is receiving the right level of help to adequately self-manage their comorbidities. However, appropriate monitoring and modification of care goals and treatments does not always appear to be occurring. For example, American research found that a diagnosis of dementia significantly reduced the likelihood that individuals with diabetes received recommended annual monitoring<sup>92</sup>, while a UK study found that people with dementia in England may be substantially less likely to receive age-related macular degeneration treatment to help prevent loss of vision<sup>93</sup>. These findings suggest that not enough is being done to reduce people with dementia's risk of illness and discomfort.



# Dementia and specific comorbidities in the UK

A person with dementia is currently at an increased risk of having underdiagnosed comorbidities, receiving poorer treatment and management for comorbidities which are diagnosed and receiving worse end of life care. The next section looks at how this relates to specific comorbidities, focussing on depression, diabetes, and urinary tract infections, with illustrative 'good' care stories for each.

## Depression and dementia

Depression, along with apathy, is the most common psychiatric manifestation seen in dementia patients<sup>94</sup>. However, the relationship between dementia and depression is complex, features overlap and each seems to be a possible risk factor, symptom or consequence of the other. Thus, identification and effective management of depression in people with dementia remains a challenging task in clinical practice<sup>95</sup>. This is reflected by research into depression rates amongst people with dementia, with the results varying substantially depending on the population sampled and means of assessment<sup>96</sup>. Overall, most well conducted population-based studies report a relatively high prevalence of depression, ranging from 8% to 30%<sup>97,98,99</sup>. For example, in a large UK study including 587 participants with dementia and 2050 with no dementia depression was present in 20.5% of the dementia group, compared with only 8.6% of those without dementia<sup>100</sup>.

There are also differences in the rates of depression depending upon the type of dementia a person has. For example, studies investigating depression in people with vascular dementia, Lewy body dementia or dementia associated with Parkinson's disease suggest that depression may be more common in these syndromes than in Alzheimer's disease<sup>101</sup>. Research also suggests that depression is often more severe in patients with Lewy body dementia<sup>102</sup>.

The consequences of depression in people with dementia are significant, and include increased burden on patients and caregivers, exacerbation of cognitive and functional decline, poor outcomes from other medical or surgical interventions, earlier admission to nursing homes, and increased mortality<sup>103</sup>.

## Prevention

The high prevalence of depression amongst people with dementia has led researchers to investigate the relationship between the two, with recent research suggesting that depression may in fact be a risk factor for dementia. People who had depression late in life were found to have twice the average risk for developing Alzheimer's disease and a 50% increased risk for vascular dementia<sup>104</sup>. Despite these findings it is still unclear exactly why depression and dementia often occur together.

However, the link between the two means that preventing depression amongst older people in general may have a knock-on effect on the rates of both dementia, and depression rates of people with dementia. Healthy habits such as good nutrition have been shown to be effective in preventing depression, along with having an active social life and participating in mentally challenging and engaging activities<sup>105</sup>. Physical activity in particular has been shown to positively affect the wellbeing of people with dementia by creating opportunities for social interaction and reducing feelings of isolation<sup>106,107</sup>.

However, people with more acute dementia require interventions to be specifically tailored to their needs. Basic daily activities, such as eating and washing, also need to be carefully planned, with active support from carers and medical staff, to ensure that they are carried out in comfort and without pain. However, there is often a disconnect between evidence and

practice in how this support is implemented. For example, research has found that despite the availability of evidence-based training manuals, there is a widespread use of non-evidence-based training and interventions by care home staff working with people with dementia<sup>108</sup>. Clearer guidance is therefore needed to ensure that commissioned training and interventions are based on robust evidence<sup>109</sup>.

### **Carers can play a key role, but they need to be looked after too**

Research looking at people with severe dementia in eight EU countries found that those residing in long-term care homes were less likely to suffer from depressive symptoms than those living in the community - 37% of the people living in the community showed signs of depression compared to 23% of those in care homes<sup>110</sup>.

This discrepancy could be in part due to the high levels of depression experienced by long term, older carers<sup>111</sup> which in turn may affect the mental health of the people they are looking after. While many carers get personal satisfaction from the caring role, they can also experience negative health, social and financial consequences that put them at a high risk of depression. For example, UK research has found that 75% of carers reported that it was hard to maintain relationships and social networks because people do not understand the impact that caring has<sup>112</sup>. Depression amongst long term older carers has been shown to have a significant effect on the mental wellbeing of the people with dementia they are looking after, with dementia patients looked after by a carer with depression more likely to develop depression themselves<sup>113</sup>. Preventing depression amongst people with dementia could therefore be better achieved by supporting the mental health of their carers. For example, more could be done to provide them with breaks from their caring duties to enable them to see friends and be physically active.

### **Diagnosis**

While the NICE guidelines for dementia<sup>114</sup> recommend that “Care packages for people with dementia should include assessment and monitoring for depression and/or anxiety”, international evidence suggests that depression in people with dementia remains severely underdiagnosed. For example, a Dutch study of nursing home residents found that while diagnosed depression rates for residents with and without dementia were virtually identical, residents with dementia (46.4%) had more depressive symptoms than residents without dementia (22.6%), suggesting a severe underdiagnosis of depression in this group<sup>115</sup>. Other international studies have had similar findings<sup>116</sup>.

A number of different factors may hinder accurate assessment. Identifying depression in someone with dementia can be difficult because it can cause some of the same symptoms as the dementia. For example, although apathy is commonly associated with depression, approximately 60% of dementia patients have apathy without depression<sup>117</sup>. However, there are symptoms which have been found to be particularly prevalent in people with dementia and depression, such as irritability<sup>118</sup>, which should alert caregivers and medical staff and help early recognition<sup>119</sup>. Frontal lobe and behavioural symptoms have also been found to be more prevalent and severe in patients with Alzheimer’s disease and depression, compared to those with just Alzheimer’s disease<sup>120</sup>.

Communication is also an issue in diagnosis, as the cognitive impairment experienced by people with dementia often makes it difficult for them to articulate their sadness, hopelessness, guilt and other feelings associated with depression<sup>121</sup>. The National Institute of Mental Health have established a formal set of guidelines for diagnosing depression in people with Alzheimer’s, which could be used to aid this process, as they reduce emphasis on verbal expression and include irritability and social isolation in their assessment.

The communication difficulties experienced by people with dementia, and the similarity of the symptoms of dementia and depression, mean that caregivers are extremely important in ensuring an accurate diagnosis of depression. For example, research evaluating 157 patient/

caregiver pairs found that asking a single question to the patient about depression failed to detect most cases of depression, while caregivers identified two-thirds of patient depression when asked this one question<sup>122</sup>. Therefore, for a diagnosis to be effective, interviews with carers and family members who know the person well need to be conducted, along with a review of the person's medical history, and a physical and mental examination<sup>123</sup>. However, this does not always appear to be occurring. UK based research has found that in 33% of care homes and 61% of hospitals, there were aspects of variable or poor care regarding how people, together with their families and carers, were being included in decisions about their care<sup>124</sup>.

## Management and treatment

Getting appropriate treatment for depression can significantly improve the quality of life of the person with dementia. Effective treatment involves many of the same elements involved in treating people without the disease - a combination of medicine, counselling, and gradual reconnection to activities and people that bring happiness<sup>125</sup>. However, these elements need to be modified in the context of the dementia.

### Medication

The final section in the NICE guidelines on dementia addressing depression states “People with dementia who also have major depressive disorder should be offered antidepressant medication<sup>126</sup>”. However, a recent NHS-funded evaluation found two commonly prescribed antidepressants had no effect compared with placebo on the depression of people with Alzheimer's disease<sup>127</sup>, calling into question the NICE guidance. This highlights the lack of robust evidence for the use of antidepressants in dementia patients, and suggests a need to change the current practice of antidepressants being the first-line treatment of depression.

The current reliance on antidepressants is highlighted by a recent UK based study which showed that while there has been a marked reduction in the use of antipsychotic drugs between 1995 and 2011 for people with dementia, there has been a steady increase in antidepressant use<sup>128</sup>.

Future research in this area should evaluate whether newer classes of antidepressants, such as venlafaxine, or antidementia medications, such as cholinesterase inhibitors, are more effective<sup>129</sup>. However, if these new drugs are shown to be effective, cautious prescribing is critical as older people are more susceptible to medication side effects, often have multiple comorbid physical illnesses, and may be taking medications that can interact with antidepressants<sup>130</sup>. For example, a UK based study found 69.5% of residents had one or more medication error relating to how their medications were prescribed, monitored, administered and/or dispensed<sup>131</sup>. Any prescribing of antidepressants should therefore include a clear plan to monitor efficacy and adverse effects.

### Treatment without drugs

While there are question marks over the role of drugs in treating depression in people with dementia, there is clear evidence that psychological therapies and tailored interventions can have a positive effect. For example, music and recreation therapy have been shown to be effective in tackling depression in people with dementia, including in severe dementia<sup>132,133</sup>. There is also increasing evidence that cognitive behavioural therapy (CBT) is effective for treating depression in people with dementia, with treatment focused on identifying beliefs associated with dementia, behavioural experimenting to test the validity of these beliefs, and increasing pleasurable activities<sup>134</sup>.

The use of these therapies is also supported by the NICE guidelines on dementia, which state “a range of tailored interventions, such as reminiscence therapy, multisensory stimulation, animal-assisted therapy and exercise, should be available for people with dementia who have depression and/or anxiety”, as well as “cognitive behavioural therapy, which may involve the active participation of their carers<sup>135</sup>”.

However, GPs face barriers in gaining access to these services. For example, a survey found that over half (55%) of GPs believe that talking treatments are the most effective way to treat mild or moderate depression, yet 78% have prescribed an antidepressant while believing an alternative would have been preferable<sup>136</sup>. A 2013 report by the mental health charity MIND, found that 58% of people were not being offered a choice in the type of therapies they received, and 40% were having to request psychological therapies rather than being offered them<sup>137</sup>. While these surveys concentrated on the general population, evidence throughout this report strongly suggests that access for people with dementia is likely to be further limited by the prioritisation of dementia over depression by medical professionals, and the communication difficulties brought about by the disease.

For people with more advanced forms of dementia, the role of carers again becomes critical in helping them to undertake the activities to help alleviate the depression. This can involve making a list of activities, people or places that the person enjoys and scheduling these things more frequently; helping the person to exercise more regularly; and finding ways that the person can contribute to family life<sup>138</sup>. However, as previously discussed, carers must be given the appropriate support to maintain their own wellbeing.

### **‘Best case’ care story**

Mr Jones is 82, and lives at home with his wife who acts as his full time carer. He has had Alzheimer’s disease for four years, and began to have episodes of depression just before the onset of his dementia. When Mr Jones first went to see his GP after becoming depressed, his doctor prescribed a series of CBT sessions to help him work through the difficulties he was having accepting the reduction in capacity he was experiencing as he got older. Mr Jones’ GP also talked to him about his lifestyle, and made some recommendations to improve his diet and level of physical activity. The changes were effective in treating the depression.

A year later Mr Jones was diagnosed with dementia. Mr Jones’ GP arranged for him to be seen by an occupational therapist to ensure that he was able to keep up with every day activities and remain independent for as long as possible. Mr Jones’ history of depression was raised, and he was directed towards a number of mentally challenging and engaging activities in the local area, specifically aimed at people with dementia. Mrs Jones was also actively involved in the meeting, and the occupational therapist highlighted actions she could take to help ensure her husband did not become depressed, including making a list of activities, people or places that Mr Jones enjoys and scheduling these things more frequently, helping Mr Jones to exercise more regularly, and finding ways that he can contribute to family life.

As Mr Jones became increasingly dependent on his wife, Mrs Jones found looking after him difficult, both mentally and physically, and went to see her GP. Her doctor prescribed a series of psychological therapy sessions, aimed at reducing anxiety and depression in people caring for a family member with dementia. The programme consisted of a series of sessions over several months, which included education about dementia, ways to find emotional support, and techniques for managing difficult behaviour<sup>139</sup>. This has helped Mrs Jones to support her husband, which has positively affected both of their mental wellbeing.

## Diabetes and dementia

The number of people with diabetes is dramatically increasing; there are currently around 3.8 million people in the UK<sup>140</sup>, rising to 5 million by 2025 with Type 2 diabetes accounting for around 90% of all cases. In similarity to dementia, diabetes is both a progressive and long-term condition. These dramatic rises, combined with the rise in number of people with dementia, means that the UK is likely to see more individuals with both diabetes and dementia in the future.

Prevalence rates of diabetes amongst people with dementia are high, with study results varying from 6% to 39%<sup>141</sup>. However, Type 2 diabetes has also been found to significantly and independently increase the risk of dementia, although researchers do not fully understand the link between the two conditions. The level of risk varies depending on the type of dementia- a review of relevant studies found that diabetes was associated with a 47% increased risk of any dementia, a 39% increased risk of Alzheimer's disease, and a 138% increased risk of vascular dementia<sup>142</sup>. People from racial backgrounds with high rates of diabetes therefore have high rates of vascular dementia, for example people from an Indian, Bangladeshi, Pakistani, or Sri Lankan backgrounds<sup>143</sup>.

### Prevention

Risk factors for Type 2 diabetes include obesity; eating too many fatty, salty and sugary foods; and too much alcohol. Studies have shown that the onset of dementia may make some people more susceptible to these risk factors as it can lead to changes in appetite, food preference, and eating habits<sup>144</sup>. For example, while under-nutrition is generally a greater problem for people with dementia, dementia can also lead to a person developing a preference for sweet flavours or savoury snack food, which can have a high calorie content. Frontotemporal dementia in particular has been shown to lead to a higher intake of sugar and carbohydrates<sup>145</sup>. Additionally, older people with greater cognitive impairment are less likely to adhere to a recommended diet<sup>146</sup>.

Regular physical activity can also help reduce diabetes risk. However, greater cognitive impairment has been found to reduce adherence to exercise<sup>147</sup>. People with dementia should therefore be encouraged and supported to continue with any physical activity they were doing before their diagnosis. Those who were not previously active should have an exercise programme incorporated into their lifestyle in the early stages of dementia as it is more likely to then be maintained as the dementia progresses. In the later stages of dementia, a high level of support from family and service providers is vital in ensuring that people with dementia remain physically active<sup>148</sup>.

### Diagnosis

A UK study of hospital in-patients found far fewer people with dementia were diagnosed with type-2 diabetes than controls without dementia<sup>149</sup>, suggesting diabetes is currently underdiagnosed in this group. Underdiagnosis may be occurring because the signs and symptoms of diabetes can be confused with those of dementia and remain neglected. For example; confusion, tiredness and weight loss are common in both dementia and untreated diabetes<sup>150</sup>. Worryingly, hypoglycaemia- a medical emergency that involves an abnormally diminished content of glucose in the blood- is a real risk to individuals with both conditions as the signs and symptoms may be mistaken for signs of worsening confusion<sup>151</sup>.

Communication is also an issue as people with dementia may be unable to recognise the symptoms of diabetes, or effectively communicate them to their carers. Therefore, any physical or mental changes should not be automatically put down to dementia, and instead be properly investigated for their cause. For example, the presence of infections such as thrush or urinary tract infections may be the only outward sign that a person has diabetes<sup>152</sup>.

Diagnosing diabetes early in people who already have dementia will ensure that the disease is regularly reviewed and managed. Medications can be started to relieve the symptoms of high blood glucose improving quality of life, for example by reducing tiredness, frequency of urination and thirst, and avoiding hospital admissions for very high blood glucose levels<sup>153</sup>.

## Management and treatment

The high rate of dementia and diabetes comorbidity means that many people who develop dementia will already have diabetes, and experience of its management and treatment. Despite this, the NICE National clinical guideline for management in primary and secondary care of type 2 diabetes does not include any reference to dementia<sup>154</sup>. This is worrying, as the changes associated with dementia, especially around memory, can lead to difficulties with self-management developing, with research showing a direct link between cognitive impairment and worse diabetes care<sup>155</sup>. For example, problems may arise such as people forgetting to take their medications, forgetting how to administer injections, and becoming unable to make decisions about interpreting blood glucose results<sup>156</sup>.

For people who develop diabetes after being diagnosed with dementia, these problems may be even more acute as they have no experience of self-managing the disease. This puts them at a greater risk of a range of problems, such as increased confusion if blood glucose levels are high and causing dehydration and distress if their usual diet is changed significantly<sup>157</sup>. The level of support required will vary depending on the severity of the dementia, with research finding that people with diabetes and low levels of cognitive function required significantly more assistance with personal care behaviour than people with diabetes alone<sup>158</sup>.

## Entering a formal care environment

When a person with diabetes and dementia enters a formal care environment, such as a care home or a hospital, care home staff and medical professionals should discuss with the patient and their family how diabetic procedures have been conducted in the past. Not doing this risks patients rejecting regimes for blood glucose monitoring and insulin administration that they are not used to<sup>159</sup>.

An annual check-up is also important, including the monitoring of their blood glucose levels, cholesterol levels and vision. However, there are question marks over whether this is occurring due to the NICE National clinical guideline for diabetes not addressing dementia<sup>160</sup>. While the guideline does recommend annual tests, by not addressing the complications brought about by dementia, such as communication difficulties, it risks some of this group slipping through the system. This has been shown to happen in other countries, with an American study finding a diagnosis of dementia significantly reducing the likelihood that individuals with diabetes received recommended annual monitoring<sup>161</sup>.

The high level of daily management needed for diabetes means that it is important for health professionals to develop individual support plans outlining each patient's distinct health and social needs<sup>162</sup>. These could be passed on to everyone involved in caring for that person, and should be reviewed and updated regularly as the dementia progresses<sup>163</sup>. This could include agreed safe blood glucose targets which aim to avoid symptomatic high blood glucose levels (hyperglycaemia), but also avoid low blood glucose levels (hypoglycaemia)<sup>164</sup>.

## Carers

Older people with cognitive impairment are less likely to adhere to exercise and to follow an appropriate diet<sup>165</sup>. Problems may therefore arise around trying to maintain glucose levels through food consumption, such as missed meals resulting in low blood glucose levels, or forgetting meals have been eaten resulting in an increased risk of high glucose levels if they eat again<sup>166</sup>.

Carers play a vital role in ensuring that these problems are addressed and the diabetes is appropriately managed. Memory loss is often the first sign of self-care neglect leading to

caregiver intervention to help a person with dementia manage their diabetes<sup>167</sup>. However, the presence of a caregiver is not automatically protective against worse diabetes care management<sup>168</sup>. Caregivers face a number of challenges and quality-of-life issues when trying to manage diabetes in patients with dementia. The behavioural and psychological symptoms of dementia often disrupt the daily diabetes care routine, such as a 'denial' of having diabetes or memory loss<sup>169</sup>. Caregivers also report that caring for both diabetes and dementia is extremely difficult, resulting in them feeling overwhelmed, and wanting more support from family and patients' healthcare providers<sup>170</sup>.

### **'Best case' care story**

Mrs Green is 83, developed Type 2 diabetes when she was in her 50's, and has had dementia for two years. She has recently begun living in a nursing home. Having had diabetes for around 30 years, Mrs Green was adept at self-managing her condition. However, as her dementia has progressed she has begun to forget to take her medications, and has found it increasingly hard to interpret her blood glucose results. Before entering the nursing home, Mrs Green's GP developed a support plan for her to be passed on to the home. This included agreed safe blood glucose targets, and recommendations for her diet. It also included prompts to arrange an annual diabetes check-up to monitor her blood glucose levels, cholesterol levels and vision. When Mrs Green first entered the nursing home, the staff also discussed with her and her daughters how she had conducted diabetic procedures in the past. Mrs Green could not remember all of the details of her regime, but her daughters were able to fill in the gaps. This helped to ensure that Mrs Green did not reject the regime for her blood glucose monitoring and insulin administration.

Mrs Green's dementia had caused her to forget to eat regular meals when she was living alone, which had resulted in her becoming slightly undernourished, and experiencing a series of 'hypos' as her blood glucose had dropped too low. The care home staff initiated a number of strategies to maximise her dietary intake, including serving one course at a time to reduce confusion, allowing extra time for her to return to her meal, and encouraging low glycaemic index dairy products when other foods were refused. The result of these measures was Mrs Green's blood glucose levels were adequately controlled, and she rarely experienced any distress when her daily diabetes management routine was being carried out.

## **Urinary tract infections and dementia**

UTIs are one of the most common infections in the older population, occurring both in the community and in long-term care settings<sup>171</sup>, and have a high mortality rate in this group<sup>172</sup>. UTIs have been found to speed up the progression of dementia as they frequently result in superimposed delirium that can accelerate cognitive decline<sup>173</sup>. UTIs also have a significant financial cost, due the large volume of patients with this type of infection.

### **Prevention**

Urinary tract infections are avoidable, or can be managed with prompt access to medical care<sup>174</sup>. However, they are extremely common amongst people with dementia, with a UK study finding that UTIs, along with pneumonia, were the principal causes of hospital admission in 41.3% of the people with dementia<sup>175</sup>.

### **Preventative care practices**

UTIs in people with dementia can often be prevented by the application of preventative care practices, which are applicable whether they are in their own home, a nursing home or a medical setting. This is because UTIs are often caused by dehydration, urine retention and

poor hygiene, which can be prevented by proper care practices<sup>176</sup>. People with dementia can become dehydrated because they do not recognise the vessel being used to administer water, which can lead to them not drinking even when they are thirsty<sup>177</sup>. It is therefore important that routines are created and familiar objects used as part of the individuals care plan<sup>178</sup>. This can be further aided by carers finding out the preferences of the person with dementia and making drinks readily available and visible.

Poor hygiene and urine retention also increase the risk of getting UTIs. Like dehydration, this risk can be averted by preventative measures built into their care plan such as ensuring that the genitals of the person with dementia are washed at least once a day<sup>179</sup>, and that they are regularly prompted to use the toilet<sup>180</sup>. However, there is a lack of awareness and understanding by some medical professionals of how dementia may affect care. An audit by the Royal College of Psychiatrists' Centre for Quality Improvement found that 41% of hospitals do not include dementia awareness training in their staff induction programmes, and under a quarter of hospitals do not provide dementia awareness training to doctors or other allied healthcare professionals<sup>181</sup>. This can potentially lead to people with dementia not having suitable care plans put in place and being put at increased risk of contracting a UTI. For example, research by the Mental Welfare Commission for Scotland looking at 52 NHS units providing longer-term care for people with dementia found that less than half (47%) of individuals with dementia had care plans which addressed their complex dementia needs and were reviewed at least every three months<sup>182</sup>. Even more worryingly, 11% of dementia patients had no care plan in place whatsoever.

## Urinary catheters

The leading cause of UTIs are indwelling catheters, which result in more than 80% of cases<sup>183</sup>. A UK study found that patients with dementia and incontinence are more likely to receive indwelling catheters than those with incontinence but without dementia<sup>184</sup>. A further study examining the case notes of patients aged 70 or over who died whilst an inpatient on an acute medical ward found that the use of urinary catheters was more frequent among patients who were documented as having dementia<sup>185</sup>. This suggests that health care practitioners providing care for people with dementia may be prioritising ease of management of patients over reducing their chance of contracting a UTI<sup>186</sup>.

The focus of healthcare professionals on ease of management of dementia patients over their optimum healthcare is further supported by research into other areas of care. For example, people with dementia are frequently given powerful drugs to manage their behaviour<sup>187</sup>. The failure to identify the causes of these behaviours may do little more than cause sedation and can lead to further cognitive decline, reduced patient activity, worsening incontinence, and falls, and make it more difficult for caregivers to provide assistance<sup>188</sup>. Current guidelines may exacerbate this situation by not going far enough to ensure that people with dementia, who are unable to give their consent, are only given drugs which are in their best interests.

Effectively educating medical staff in proper catheter care could be a way of addressing this issue, as it has been found to reduce overall catheter usage and the associated UTIs. For example, Brighton and Sussex University Hospitals Trust have worked to reduce its overall catheter usage after finding catheters were being used too often and for too long, sometimes without clinical need. The trust developed a comprehensive catheter action plan, with education and training as key. The work has helped to reduce catheter use from 24% in 2007 to 16.7% in January 2010. The incidence of CAUTIs (catheter-associated urinary tract infections) has fallen over the same period from 18% to 13.3%, and there are fewer A&E attendances and admissions with catheter related problems<sup>189</sup>.

However, while Brighton and Sussex University Hospitals Trust's scheme has shown that good catheter care can result in a reduction of UTIs, it does not specifically address the complications of looking after someone with dementia, such as the issues around communication. With research showing that people with dementia are more likely to be fitted



with a catheter in the first place, good catheter care guidelines must also include processes for addressing the complications of caring for someone with dementia.

## Diagnosis

The diagnosis of UTIs is extremely difficult as there are currently no available diagnostic techniques for demonstrating that bacteria have invaded the tissues of the urinary tract. Instead, diagnosis is clinical and is based on symptoms or signs of inflammation of the urinary tract<sup>190</sup>. Diagnosis of UTIs in people with dementia, especially those in the later stages, can be made more difficult by the patient's inability to communicate to those around them that something is wrong. This difficulty is exacerbated by the symptoms of UTIs in people with dementia often mimicking those resulting from a progression of the dementia itself such as confusion, agitation or withdrawal<sup>191</sup>.

In consequence, it is vital that those caring for people with dementia are familiar with the symptoms of a UTI, and react to any sudden or unexplained changes in behaviour by seeking medical help (in the case of carers) or by carrying out an examination/tests (in the case of medical professionals)<sup>192</sup>.

A report by the Care Quality Commission found that having a checklist of common symptoms that care staff routinely monitor, giving an explanation of potential risks and the rationale for the close observations and actions to be taken, helped to ensure that staff responded quickly to health changes of people with dementia<sup>193</sup>. It is also important for those people with dementia who are at greater risk of UTIs, for example those with incontinence, to have this highlighted in their care plans so that carers are made aware of symptoms to watch out for that may indicate a urinary tract infection. For this to occur a comprehensive assessment of the person's care needs has to take place on their admission to a service and at regular intervals<sup>194</sup>.

However, a survey by the Care Quality Commission (CQC) found that 29% of care homes and 56% of hospitals were found to have aspects of variable or poor practice where assessments of people with dementia were not comprehensive in identifying all of a person's care needs<sup>195</sup>.

## Management and treatment

When a diagnosis has been made, urinary tract infections can be effectively managed and treated by GPs in the community, often through a course of antibiotics. However, along with pneumonia, they are the principal cause of admission to hospital for people with dementia. This suggests that GPs are sometimes admitting people with dementia to hospital for UTIs when they could be effectively treated in their own home or care home. Research highlights that this may be the result of doctors not having a good knowledge of dementia and how to best treat someone with both the disease and a UTI. For example, a survey of GPs found that only 37% of GPs said that they had adequate basic training on dementia<sup>196</sup>.

However, GPs do have a number of alternatives to hospital which they could consider if they are unsure of their diagnosis or the best course of action. These include discussing the case with the usual or out of hours GP, the duty geriatrician at the local acute hospital or the local psychogeriatrician, or arranging an overnight community nursing service or hospital at home service<sup>197</sup>. Treating UTIs in a community setting, unless there are severe complications, is preferable as admission to hospital can have potentially disastrous consequences for someone with dementia as is likely to further destabilise them and risks a long unsettled inpatient stay and potential unnecessary care home placement on discharge<sup>198</sup>. For example, research has found that once in hospital 24.0% of people with severe cognitive impairment and either UTIs or pneumonia die during admission<sup>199</sup>.

## Care that isn't person centred

The high mortality rate of people with dementia and UTIs once they enter the hospital setting suggests that they are receiving poor quality care that does not take into account the complications brought about by their dementia, and instead focusses purely on the UTI.

This focus on a single condition is endemic in how the public health system is arranged. For example, the Nice Quality standard for urinary tract infections in adults, which covers the management of suspected community-acquired bacterial urinary tract infection<sup>200</sup>, does not include any specific guidance on managing and treating UTIs in people with dementia.

### **‘Best case’ care story**

Mrs Smith has just moved into a care home. She has medium stage dementia, suffers from mild incontinence and has a history of UTIs. When Mrs Smith was admitted to the home staff carried out an assessment of her care needs, and spoke with her and her family to gain more information on her history and to get to know her personally.

Her care plan, developed by the home, takes into account her heightened risk of UTIs which results from both her dementia and incontinence. She receives all of her drinks in the same cup, to help ensure that she remembers to drink and doesn’t become dehydrated. The amount of water that Mrs Smith is drinking is also monitored and recorded by the care staff, and she is encouraged to drink more if she has not drunk 1.6 litres of fluid each day. Her care plan also includes regular prompts to go to the toilet, both during the day and night, to help ensure that her incontinence does not result in her being left in soiled underwear. When helping Mrs Smith to go to the toilet, each carer ensures that she is wiped from ‘front to back’ to avoid the spread of bacteria, and she receives a full body wash at least once a day. Mrs Smith has her care needs regularly assessed, and reassessed after any changes in her behaviour or condition.

These preventative measures dramatically reduced the incidence of UTIs suffered by Mrs Smith. However, after nearly a year in the home she does develop a UTI which results in her behaviour dramatically changing, with increased confusion and withdrawal. Her carers notice her change in behaviour immediately and suspect a UTI as this risk is highlighted in her care plan, and her notes also include information on the symptoms of this type of infection.

Mrs Smith’s GP is contacted immediately, and her carers highlight her history of UTIs, her mild incontinence and the sudden behavioural changes. The GP carries out a physical examination of Mrs Smith, and concludes that she has contracted an infection. She is put on a short course of antibiotics which clear up the UTI before any complications occur as it has been caught quickly. Her behaviour returns to normal.

Mrs Smith’s GP gives detailed information about the incident to the care home, along with suggested changes to her care. The care home update Mrs Smith’s records to reflect the changes indicated by the GP and tell staff about the changes to her care.

# Conclusion

We have investigated the relationship between dementia and comorbid conditions, with a specific focus on the situation in the UK. We have looked at how a diagnosis of dementia can affect the prevention, diagnosis, treatment and management of comorbid conditions, highlighting the differences between people with dementia and the general population. We have also investigated why these differences are occurring, and how having dementia may affect the prevention, diagnosis, treatment and management of specific comorbidities in the UK, focussing on depression, diabetes, and urinary tract infections, with illustrative 'good' care stories for each.

Our report highlights that while dementia is often viewed as an isolated condition, this patient group suffer from a high prevalence of comorbid medical conditions, with a number of conditions appearing to be "significantly associated" with dementia, including congestive heart failure and cerebrovascular disease. However, despite the prevalence of comorbidities amongst people with dementia, we have found that this group may be receiving poorer levels of care as they suffer a significantly faster decline in daily functioning, a reduced quality of life, and die earlier than people who have the same comorbidities, but do not have dementia.

The costs to the UK of treating and caring for people with dementia are considerable, and are likely to grow as our ageing population results in more people with the disease. We have demonstrated that untreated comorbidities in people with dementia may be significantly adding to this cost by speeding up the cognitive decline of this group. We have shown how this relates to specific comorbidities, highlighting a potential total net loss of approximately £377 million for people with dementia and diabetes, £115.7 million for people with dementia and UTIs, and £501.7 million for people with dementia and depression (see appendix 1).

The care problems faced by people with dementia have been found to be present across the patient's journey, with a diagnosis of dementia negatively affecting the prevention, diagnosis, treatment and management of comorbid conditions in the UK. Many of the comorbid conditions common amongst people with dementia are preventable, suggesting a failure in the care of this patient group. People with dementia are also more likely to have undiagnosed comorbid conditions, which are often only being detected once the symptoms of the comorbidity have become severe. They are also less likely to receive the same help to manage and treat their comorbidities than people without dementia.

This report has identified six key areas which appear to be leading to this lack of parity for people with dementia and comorbidities compared to the general population, and should be the focus of policy and practice change - atypical systems, communication difficulties, a failure by the health system to recognise the individual as a whole, a knowledge gap of hospital staff and carers in caring for people with dementia and comorbidities, poor medication management, and a lack of support to aid self-management and poor monitoring of comorbidities by health professionals.

However, the relevance of each of these areas varies depending upon the particular comorbidity being addressed, for example whether it is a physical or psychological condition and whether it arises before or after the development of dementia, with the three conditions concentrated in this report each being found to present particular challenges and gaps in care.

Therefore, for parity of care to be realised for people with dementia, is vital that health policies and practices developed for individual health conditions also take into account the specific challenges each condition presents for caring for someone with the dementia. It is only by doing this that we will be able to tackle the disproportionately negative impact comorbidities currently have on the daily functioning, quality of life, and mortality of this patient group in the UK.

We have set out seven recommendations which we believe will help to ensure that parity occurs:

1. The National Institute for Health and Care Excellence (NICE) must update its condition specific guidelines to take into account the needs of a people with dementia in order to ensure this group receive the same level of care as the rest of the population.
2. Care homes should modify the care plans of residents with dementia to include checklists covering the symptoms of common comorbidities (such as UTIs) to help ensure early diagnosis and treatment.
3. Health professionals must involve people with dementia, their carers and families in every decision about their care to improve both the diagnosis and management of comorbidities.
4. Health Education England should consider broadening its tier one dementia awareness training to include how dementia may affect care for both short and long term conditions.
5. Health trusts should develop comprehensive catheter action plans, based around staff education and training, to reduce the incidence of UTIs in people with dementia through unnecessary catheter usage.
6. The Care Quality Commission (CQC) should consider making it mandatory for care homes to undertake annual check-ups for residents with dementia and diabetes where their blood glucose levels, cholesterol levels and vision are monitored.
7. Clinical Commissioning Groups (CCGs) should commission a wide range of psychological therapies at a suitable capacity to ensure that GPs are not reliant on drugs to treat depression in dementia patients.

# Appendix 1

## The (indirect) impact of untreated comorbidities on the cost of dementia

Assessing the impact of comorbidities on the costs for dementia care is problematic for a number of reasons: on one side, retrospective studies might underestimate the cost of comorbidities given that they tend to be underdiagnosed in dementia patients<sup>201</sup>; on the other, randomised controlled trials comparing a group of patients with mild dementia to one with mild dementia and a comorbidity<sup>202</sup> miss out on a key relationship between dementia and comorbidities: comorbidities make dementia worse.

## Faster cognitive decline as the key cost of a comorbidity

Caring for patients with more severe forms of dementia costs more, especially in terms of unpaid care for people living in the community (see table 1). Therefore, by speeding up the cognitive decline, comorbidities increase financial costs, since a patient with mild dementia who would cost an average of £26,212 a year will develop moderate or severe dementia and cost £39,294/ £41,187 a year. Information on annual cost of care (health care, social care and unpaid care) can be found in the 2014 report by the Alzheimer Society “Dementia UK Update”<sup>203</sup>.

**Table 1:** Average annual cost per person with dementia, by severity (2012/13 prices)

	Healthcare	Social care	Unpaid care	Other	Total Costs
People with dementia living in the community (average cost)					
Mild dementia	£2,751	£3,121	£19,714	£137	£25,723
Moderate dementia	£2,695	£7,772	£32,237	£137	£42,841
Severe dementia	£11,258	£10,321	£33,482	£136	£55,197
All severity levels	£3,152	£4,054	£21,956	£137	£29,298
<i>Sector as % cost of total</i>	<i>10.8%</i>	<i>13.8%</i>	<i>74.9%</i>	<i>0.5%</i>	<i>100%</i>
People with dementia living in residential care (average cost)					
Mild dementia	£4,504	£24,737	£1,067	£136	£30,444
Moderate dementia	£9,438	£25,715	£2,901	£136	£38,190
Severe dementia	£8,689	£25,874	£2,119	£136	£36,817
<i>All severity levels</i>	<i>£8,542</i>	<i>£25,610</i>	<i>£2,450</i>	<i>£136</i>	<i>£36,738</i>
<i>Sector as % cost of total</i>	<i>23.3%</i>	<i>69.7%</i>	<i>6.7%</i>	<i>0.4%</i>	<i>100%</i>
All settings (average cost)					
Mild dementia	£2,932	£5,362	£17,781	£137	£26,212
Moderate dementia	£7,837	£21,455	£9,865	£136	£39,294
Severe dementia	£9,300	£22,176	£9,575	£136	£41,187
<i>All severity levels</i>	<i>£5,285</i>	<i>£12,584</i>	<i>£14,237</i>	<i>£136</i>	<i>£32,242</i>
<i>Sector as % cost of total</i>	<i>16.4%</i>	<i>39.0%</i>	<i>44.2%</i>	<i>0.4%</i>	<i>100%</i>

Source: Dementia UK Update 2014

**In this section, we model how untreated comorbidities in people with dementia can increase costs by causing a deterioration in the dementia.**

Previous research has shown that the cognitive decline in dementia patients who have comorbidities, for instance dementia and type 2 diabetes<sup>204</sup>, is **one to two years faster**<sup>205</sup>. For this reason, one sensible way to assess the impact of comorbidities on the cost of dementia is to calculate how many patients are likely to see their condition deteriorate faster, and see the increase in total costs.

In order to do so, we first calculate the number of people likely to be affected by dementia and one of the following specific comorbidities: diabetes, urinary tract infection and depression. Because comorbidities are often underdiagnosed in dementia patients, we apply the same age specific prevalence rates as found in the general population. We then calculate how many of those affected by dementia and one comorbidity are likely to have Mild, Moderate or Severe dementia by applying the prevalence rates by severity of the condition as given by the ILC-UK’s report ‘Preventing dementia: a provocation’<sup>206</sup>. Finally, we calculate the difference in aggregate cost if all of the patients with dementia and a comorbidity get worse, i.e. shift from mild to moderate dementia, from moderate to severe and from severe to death.

Our estimates are likely to be conservative because we are simply assuming that prevalence rates for a comorbidity in dementia sufferers are the same as in the general population, while in fact they could be higher; however, since comorbidities in dementia patients are likely to be underdiagnosed and we do not have exact data, a more conservative approach seems adequate.

**Case 1: Dementia and Diabetes**

We first estimate the approximate number of people who might have dementia and diabetes, by applying the prevalence rates for diabetes to the total number of patients with dementia by age group. We are aware of the fact that prevalence rates of diabetes among dementia sufferers might differ from those found among the general population, but for the sake of this exercise we will just assume that they are the same.

On average 17.7% of men and 11.4% of women aged 65-74 suffer from diabetes, with the proportion increasing to 20.4% for men and 16.4% for women over 75<sup>207</sup>. By applying the same prevalence rates to the population with dementia, we would have a total of approximately 140,000 people (men + women) aged 65+ with dementia and diabetes (see table 2).

**Table 2:** Number of people with dementia and diabetes (estimated)

	People with dementia	
	Men	Women
65-74	64,718	74,459
75+	209,860	432,384
	Prevalence diabetes	
	Men	Women
65-74	17.7%	11.4%
75+	20.4%	16.4%
	People with dementia and diabetes	
	Men	Women
65-74	11,455	8,488
75+	42,811	77,717

Source: authors’ calculations using Alzheimer UK Dementia Update (2014) prevalence rates for dementia, and Health Survey England 2013<sup>208</sup> prevalence rates for diabetes.

We then estimate the proportion of people with dementia and diabetes by severity of the condition (mild/moderate/severe)<sup>209</sup> and find 77,772 people are likely to have mild dementia and diabetes; 45,093 people with moderate dementia and diabetes, and about 17,607 people with severe dementia and diabetes (see table 2).

**Table 3:** Number of people with dementia and diabetes (estimated) by severity of the condition

	Dementia			Dementia + Diabetes (est)		
	65–74	75+	Total	65–74	75+	Total
Mild	85,872	366,079	451,951	12,385	65,387	77,772
Moderate	44,536	202,307	246,843	6,222	38,871	45,093
Severe	8,768	73,858	82,626	1,336	16,271	17,607
<i>Population</i>	139,176	642,244	781,420	19,943	120,529	140,472

Source: authors' calculations

If we assume that cognitive function in patients with both dementia and diabetes declines 2 years faster than in patient with dementia only, then we will have that in the first year the 77,772 patients with mild dementia will develop moderate dementia, the 45,093 with moderate dementia will develop severe dementia, while the remaining 17,607 with severe dementia will die. So, the first and more dramatic cost incurred is the potential loss of over 17,000 lives.

As for the monetary costs, we estimate total expenditure on care for dementia by age group and severity of dementia and calculate the additional cost due to the presence of diabetes – seen as a shifting factor (table 4).

**Table 4:** Total annual cost of care for dementia and diabetes (by setting)

	Cost if dementia Only (in million)	Cost accounting for Diabetes (in million)	Difference
People with dementia living in the community (average cost)			
Mild vs. moderate	£2,000.53	£3,331.83	£1,331.30
Moderate vs. severe	£1,931.83	£2,489.00	£557.17
Severe vs. death	£971.85	£0.00	-£971.85
<i>Total</i>	£4,904.21	£5,820.83	£916.62
People with dementia living in residential care (average cost)			
Mild vs. moderate	£2,367.69	£2,970.11	£602.42
Moderate vs. severe	£1,722.10	£1,660.19	-£61.91
Severe vs. death	£648.24	£0.00	-£648.24
<i>Total</i>	£4,738.03	£4,630.30	-£107.73
All settings (average cost)			
Mild vs. moderate	£2,038.56	£3,055.97	£1,017.41
Moderate vs. severe	£1,771.88	£1,857.25	£85.36
Severe vs. death	£725.18	£0.00	-£725.18
<i>Total</i>	£4,535.62	£4,913.22	£377.59

Source: authors' calculations

On average, the 77,772 patients who developed moderate dementia due to the presence of diabetes would cost an additional £1 billion and the 45,093 patients who developed severe dementia would cost an additional £85 million. Even if we factor in the potential cost savings

of £725 million due to the 17,607 people with severe dementia who died, we would still have a total net loss of approximately £377 million.

However, table 3 also shows a substantial difference between additional cost of care for people with dementia living in the community and additional cost of care for those living in residential care, with the latter potentially saving £107 million.

## Case 2: Dementia and Urinary Tract Infections

We can repeat the same line of reasoning for the impact of Urinary Tract Infections (UTIs) on people with dementia.

UTIs are more common in women than in men. It's estimated half of all women in the UK will have a UTI at least once in their life, and 1 in 2,000 healthy men will develop one each year<sup>210</sup>. Annual incidence of UTIs in the general population is 7-8% for women over 60, 20% for women over 80 and 3% for men aged 60-70 and 10% for men aged over 80. So the total number of people with dementia and UTIs would be of approximately 101,781 (70% of which women aged 80+)<sup>211</sup>.

We estimate the approximate number of people with dementia who might get UTIs by applying the prevalence rates for UTIs to the total number of patients with dementia by age group; we therefore have a total of 101,781 people (men + women) aged 65+ with dementia and UTIs (see table 4).

**Table 5:** Number of people with dementia and UTIs (estimated)

	Men	Women	Total
65-79	3,499	11,328	14,828
80+	15,793	71,160	86,953
<i>Total</i>	19,293	82,488	101,781

Source: authors' calculations

We then estimate the proportion of people likely to have dementia and UTIs by severity of the condition (mild/moderate/severe)<sup>209</sup> and find 52,932 people likely to have mild dementia and UTIs; 33,314 people with moderate dementia and UTIs, and about 15,534 people with severe dementia and UTIs (see table 6).

**Table 6:** Number of people with dementia and UTIs (estimated) by severity of the condition

	Dementia			Dementia + UTIs (est)		
	65-79	80+	Total	65-79	80+	Total
Mild	159,767	274,380	434,147	8,956	43,976	52,932
Moderate	83,734	166,918	250,653	4,641	28,673	33,314
Severe	24,189	72,432	96,621	1,231	14,304	15,534
<i>Population</i>	267,690	513,730	781,421	14,828	86,953	101,781

Source: authors' calculations

Note: the number of people with dementia by age groups is different from what we reported in table 2 because we are considering different age groups.

For the sake of argument, we will assume that UTIs do not get treated and thus lead to an accelerated cognitive decline in the affected dementia patients. In table 6 we report the potential extra costs in dementia care due to the presence of UTIs as comorbidities.



**Table 7: Total annual cost of care for dementia and UTIs**

	Cost if dementia only (in million)	Cost accounting for UTIs (in million)	Difference
People with dementia living in the community (average cost)			
Mild vs. moderate	£1,361.6	£2,267.7	£906.1
Moderate vs. severe	£1,427.2	£1,838.8	£411.6
Severe vs. death	£857.4	£0.0	-£857.4
<i>Total</i>	£3,646.2	£4,106.5	£460.3
People with dementia living in residential care (average cost)			
Mild vs. moderate	£1,611.5	£2,021.5	£410.0
Moderate vs. severe	£1,272.3	£1,226.5	-£45.7
Severe vs. death	£571.9	£0.0	-£571.9
<i>Total</i>	£3,455.6	£3,248.0	-£207.6
All settings (average cost)			
Mild vs. moderate	£1,387.5	£2,079.9	£692.5
Moderate vs. severe	£1,309.0	£1,372.1	£63.1
Severe vs. death	£639.8	£0.0	-£639.8
<i>Total</i>	£3,336.3	£3,452.0	£115.7

Source: authors' calculations

By speeding up the cognitive decline, an additional 15,534 lives would be lost in the first year. The 52,932 patients who would have mild dementia if treated for UTIs but developed moderate dementia because UTIs were left untreated would cost an additional £692.5 million, the 33,314 patients who would have moderate dementia but developed severe dementia would cost an additional £63 million. However, the premature death of 15,534 severe dementia sufferers would result in a (rather grim) cost saving of £640 million total, and therefore the total cost of leaving UTIs untreated would reach approximately £115.7 million.

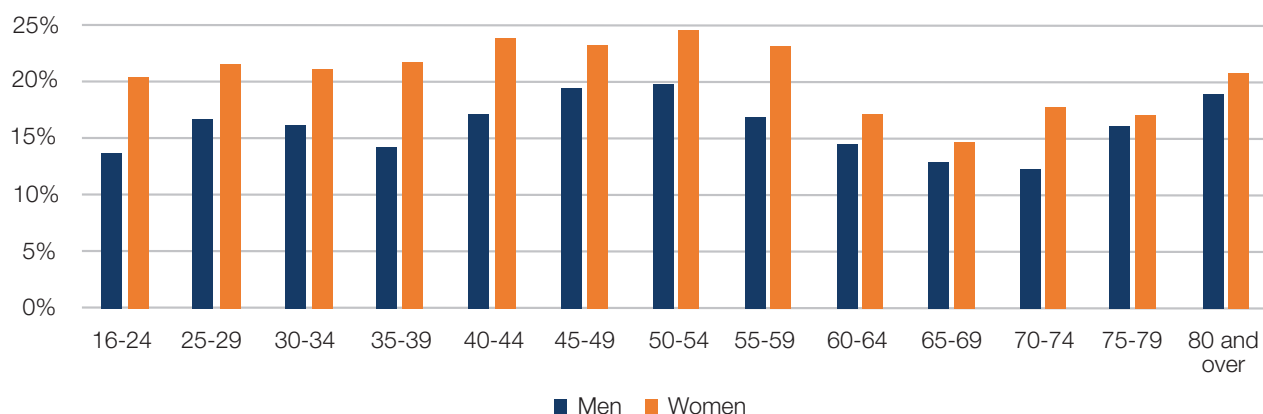
Once again, average costs would increase mainly for the care of people with dementia living in the community (£457.5 million) while the cost of residential care might decrease by about £208 million.

### Case 3: Dementia and Depression

Depression is particularly common in people who have vascular dementia or Parkinson's dementia<sup>212</sup>.

To estimate the prevalence of depression in the general population we have drawn information from *Understanding Society*, a longitudinal survey representative of the UK population.<sup>213</sup> In the graph below, we can see that the prevalence of depression is quite constant with age, albeit decreasing after age 60, increasing again after age 70, and consistently higher for women until age 75, when prevalence rates seem to converge.

**Figure 1:** Respondents with some indications of anxiety and depressions, (2010-11)



Source: Understanding Society (2010/11)

By applying the same prevalence rates to the population with dementia aged 65+, we would find approximately 172,000 people with both dementia and depression (see table 8).

**Table 8:** Number of people with dementia and depression (estimated)

	Men	Women	Total
65 - 69	4,806	7,429	12,360
70 - 74	8,360	12,943	21,205
75 - 79	13,016	22,080	35,178
80 and over	30,007	74,362	103,774
<i>Total</i>	<i>56,189</i>	<i>116,814</i>	<i>172,516</i>

Source: authors' calculations

We then break down the proportion of people likely to have dementia and depression by severity of the condition (mild/moderate/severe) and find 96,335 people likely to have mild dementia and depression; 55,425 people with moderate dementia and depression, and about 20,961 people with severe dementia and depression (see table 8).

**Table 9:** Number of people with dementia and depression (estimated) by severity of the condition

	65 - 69	70 - 74	75 - 79	80 and over	Total
Mild	7,626	13,253	20,052	55,425	96,355
Moderate	3,955	6,446	11,081	33,718	55,200
Severe	779	1,506	4,046	14,631	20,961
Total	12,360	21,205	35,178	103,774	172,516

Source: author's calculations

Note: the number of people with dementia by age groups is different from what we reported in table 2 and 5 because we are considering different age groups.

Even in this case, we will assume that depression does not get treated and thus leads to a faster cognitive decline in the affected dementia patients. In table 10 we report the potential extra costs in dementia care due to the presence of depression as a comorbidity.

**Table 10:** Total annual cost of care for dementia and depression

	Cost if dementia only (in million)	Cost accounting for depression (in million)	Difference
People with dementia living in the community (average cost)			
Mild vs. moderate	£2,478.5	£4,127.9	£1,649.4
Moderate vs. severe	£2,364.8	£3,046.9	£682.1
Severe vs. death	£1,157.0	£0.0	-£1,157.0
<i>Total</i>	£6,000.3	£7,174.8	£1,174.5
People with dementia living in residential care (average cost)			
Mild vs. moderate	£2,933.43	£3,679.80	£746.37
Moderate vs. severe	£2,108.09	£2,032.30	-£75.79
Severe vs. death	£771.72	£0.00	-£771.72
<i>Total</i>	£5,813.24	£5,712.10	-£101.14
All settings (average cost)			
Mild vs. moderate	£2,525.7	£3,786.2	£1,260.5
Moderate vs. severe	£2,169.0	£2,273.5	£104.5
Severe vs. death	£863.3	£0.0	-£863.3
<i>Total</i>	£5,558.0	£6,059.7	£501.7

Source: author's calculations

By speeding up the cognitive decline, 20,961 lives would be lost. Furthermore, 96,355 patients would be shifted from mild to moderate dementia and would cost an additional £1.3 billion; the 55,200 patients who would have suffered from moderate dementia but developed severe dementia would cost an additional £104.5 million. In total, leaving depression untreated in patients suffering from dementia might cost an additional £501.7 million.

Like in the previous cases, average costs would increase mainly for the care of people with dementia living in the community (+ £1.2 billion) while the cost of residential care might decrease by about £100 million.

# Endnotes

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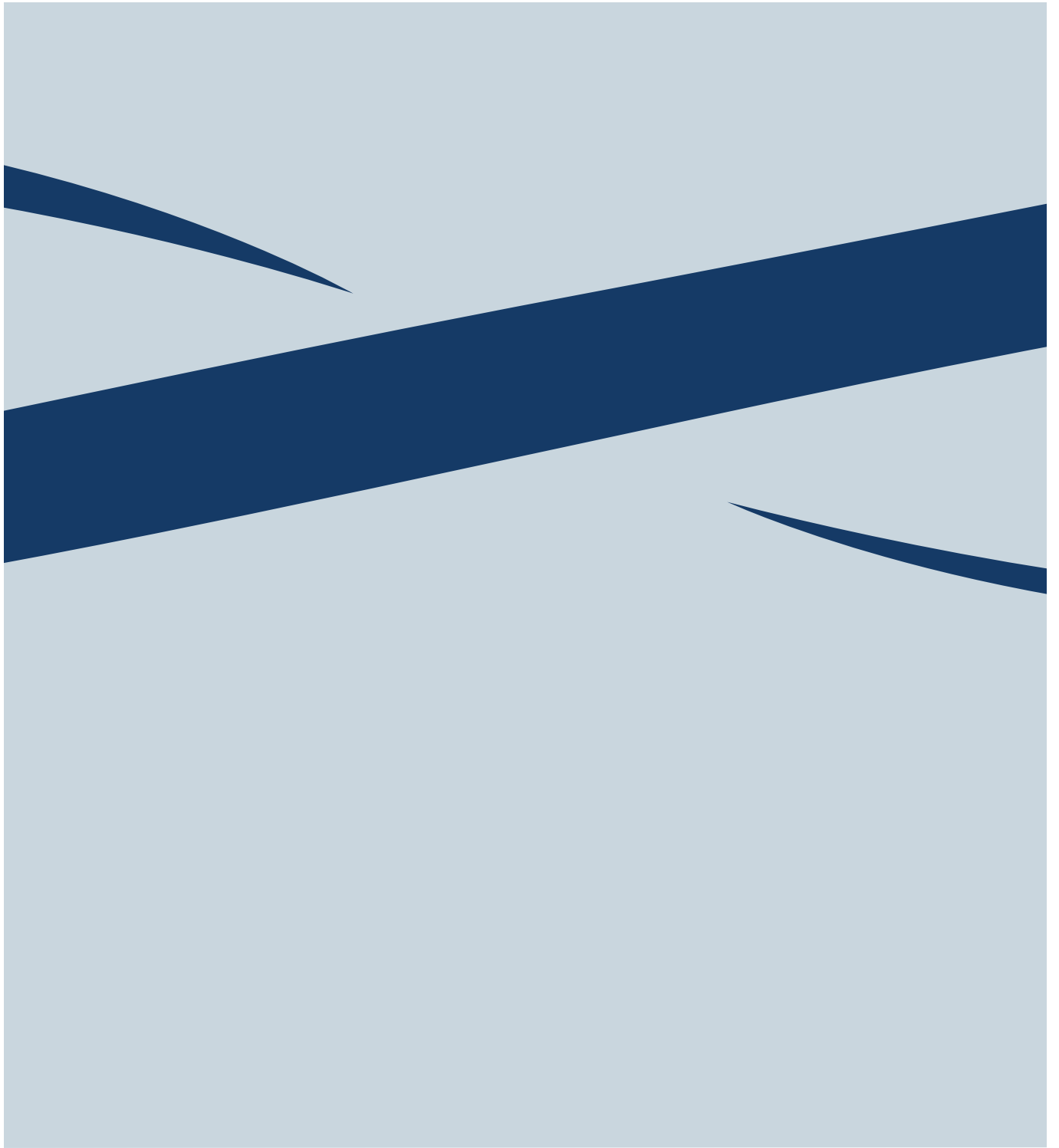
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