Excess winter deaths among people living with Alzheimer’s Disease or related dementias.

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Chris Morris & Christine Liddell
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Triangulation

Triangulation is defined as the use of multiple methods – mainly qualitative and quantitative – in studying the same phenomenon. This combination is, ideally, used by multiple researchers at the same time, each scrutinising multiple sources of data and applying a range of... interpretations. This process can often reveal complementarity, convergence, and dissonance among findings. It widens and deepens understanding¹.

¹Hussein 2009
Acknowledgements

The time and generosity of carers in helping us understand a phenomenon hitherto almost unexamined is very gratefully acknowledged. We also thank AgeNI, and several health professionals in Northern Ireland, who generously volunteered their time and expertise.

The financial support of the Chesshire Lehmann Fund is most gratefully acknowledged, as is the guidance and mentorship given to us by their Trustees.

The generous assistance of colleagues in NISRA (Northern Ireland Statistics Research Agency) and ONS (Office for National Statistics) is also very gratefully acknowledged.
Executive Summary

The original title of our proposal to the Cheshire Lehmann Fund was

"Understanding the causal pathways connecting dementia and Alzheimer's Disease with risk of excess winter mortality."

We believe that this report has covered a great deal of ground in furthering that understanding. It has done so largely through triangulation - a research technique by which a variety of different approaches, evidence sources, and people are brought to bear on a single issue. This report is, in every sense, triangulated. The single issue of concern is to identify at least some possible explanations for recently published data from the UK’s Office for National Statistics, relating to a high rate of excess winter deaths among people who were living with Alzheimer’s Disease or related dementias. The evidence base brought to bear on the issue includes analysis of mortality statistics in England, Scotland, Wales and Northern Ireland, reviews of relevant scientific publications, as well as insights gained from informal interviews with carers, both familial and professional.

Under guidance following submission of our progress report six months ago, the research comprises two main strands, reported here in the first two sections.

Section 1 analyses mortality data from England, Scotland, Wales and Northern Ireland (1991-2013) focusing on excess winter deaths related to Alzheimer’s Disease and related dementias (ADRD), and comparing the excess ratio to that evident for other causes of death. Despite many changes in how deaths associated with mental health were coded over that 22-year period, ADRD emerges, proportionally, as the second most common cause of excess winter deaths in the UK, ahead of cardiovascular and behind only respiratory causes. Until now, cardiovascular causes had been traditionally construed as the only other major sources of excess winter deaths over and above respiratory causes, so this finding (particularly the longstanding nature of excess winter death risk for people living with ADRD) is ground-breaking.

Section 2 seeks insights from carers, and describes the results of long conversations with men and women who look after people living with ADRD. These help us understand the extent to which many different disabilities associated with ADRD make home heating and energy efficiency routines increasingly problematic for people still living semi-independently. In fact,
their 2 most basic human needs – shelter and food – appear to be two of the earliest areas where competence disintegrates. Among the carers we spoke to, none were able to leave home heating and energy management, or food purchasing and preparation, to the people they were looking after.

Section 3 brings synthesis to the findings, and seeks explanations for them. A reasonably large number of studies have sought physiological explanations for disturbances in temperature regulation that could be attributed to cortical deterioration in people living with ADRD, with more occasional studies that have focused on difficulties in making behavioural adjustments to cold. However, by and large the biomedical evidence base offers little in the way of consistent or rigorous findings, and it remains uncertain as to whether people living with ADRD experience “real” disturbances in thermoregulation, or rather perceive themselves to be cold when they may not be.

Much greater consistency is found in the accounts of carers, which highlight the extent to which temperature regulation as a whole – affecting both heat and cold – may become disrupted in people living with ADRD; these accounts also provide a wide-ranging set of explanations for how this is manifest in people’s daily lives. It is also clear that neither carers nor the people they look after have been told much about solutions that could ameliorate these vulnerabilities.

The Section ends by considering some of the implications of the report’s findings, outlining useful areas for further research, and even more important, ways in which many of the factors which exacerbate risk for excess winter death can be ameliorated. It includes a list of recommendations which emanate from the findings.

In summary, the report concludes that there may be myriad contributors to the raised likelihood of people living with ADRD dying in colder weather; most have seldom been noted, and together they create something akin to a perfect storm of cumulative risk. It is possible that the diverse contributors to more people with ADRD dying in winter have simply been too mundane, too numerous, and too multi-factorial to expose a consistent pattern, and so this phenomenon has failed thus far to reach public attention. However, as with any trajectory of cumulative risk, finding ways to remove even a few risk factors from the mix will substantively lower people’s vulnerability. For that reason, ensuring that some of these findings translate quickly into remedial actions is especially apposite.
Section 1
Excess winter mortality indices associated with Alzheimer’s Disease and related dementias

“Mortality data from Scotland and Northern Ireland are to be analysed, focusing on excess winter deaths related to AD and dementia, and comparing the excess ratio to that evident for other causes of death (date range of 1990/1 to 2012/3).”

Introduction

Dementia is a generic term that describes a complex cognitive decline commonly linked to changes in mood, behaviour and personality (Ritchie and Lovestone, 2002). There are two main branches of dementia:

- primary degenerative dementias, e.g. Alzheimer’s
- dementias secondary to other disease processes such as Parkinson’s dementia.

Alzheimer’s disease is the most prevalent form of dementia in the UK, as well as Europe and North America. In the UK 60% of those diagnosed with dementia have Alzheimer’s and 20% vascular dementia (DOH, 2012); people may also experience a mixture of dementia types. Collectively, the spectrum is commonly referred to as Alzheimer’s Disease or related dementias (ADRD).

An accurate picture of ADRD in the UK is hard to fully capture as it is estimated only 50% of people ever reach a formal diagnosis. Estimates for the number of people with dementia in the UK range from 670,000 (DOH, 2012) to over 800,000 (Lakey et al., 2012). ADRD is estimated to cost the UK £23bn per year mainly split between:

- social care costs, 40% or £9bn
- unpaid carers, 55% or £12.4bn (Luengo-Fernandez et al., 2012).

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2 Excerpt from the grant proposal submitted to the Chesshire Lehmann Foundation
It is anticipated that in 30 years, due to our ageing population, the number of people with dementia will double in the UK (DOH, 2012; Lakey et al., 2012). Thus there is an ongoing need for research with the aim of reducing the harms and economic burdens associated with ADRD.

**Calculating excess winter deaths**

A standard international methodology is used to allow comparison of excess winter death rates in different countries and across time. As recently described by Fowler et al. (2014) an excess winter death index (EWDi) is calculated by comparing the number of deaths that occur in:

- the four months of winter (these are pre-designated as December to March in the Northern hemisphere)
- the four autumn months preceding that winter (August to November)
- the four spring months following on from that winter (April to July)

For example, if there are:

- 300 deaths from ADRD in August to November
- 300 deaths from ADRD in the subsequent December to March
- 100 deaths from ADRD in the following April to July

Then the excess winter death rate is calculated as follows:

Winter deaths over 3 months = 300 or 100 per month on average

Non-winter deaths over 6 months = 400 or 67 per month on average

Excess winter deaths = 33 per month of winter.

Percentage excess winter deaths = \( \frac{33}{67} \times 100 = 49.25\% \).

In the present report, we have converted this to an EWD index of 49.25.

**Excess winter deaths, dementia and Alzheimer’s Disease**

For more than 25 years, excess winter deaths have been associated with a few specific causes of death, most notably respiratory and cardiovascular causes. Recently, however, the UK Office for National Statistics has begun citing excess winter deaths for England and Wales which are additionally attributable to dementia and Alzheimer’s Disease. Table 1 provides a summary of
the ONS review of data (2009/10 to 2012/13). This indicates that the excess winter death rate for dementia or Alzheimer’s Disease (ADRD) in England and Wales, since the winter of 2009/10, has ranged from 29% to 43%. The magnitude of excess winter effect approximated twice that for deaths from circulatory disease, making ADRD the second-most common cause of death to have an excess winter effect. In each of these years, more than 2,400 excess winter deaths were attributable to ADRD.

Table 1: Percentage of excess winter deaths 2009/10 to 2012/13: England and Wales (all ages)

<table>
<thead>
<tr>
<th>Cause</th>
<th>Respiratory</th>
<th>ADRD</th>
<th>Circulatory</th>
<th>Injury/ Poisoning</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>43%</td>
<td>35%</td>
<td>20%</td>
<td>11%</td>
</tr>
<tr>
<td>2010/11</td>
<td>51%</td>
<td>43%</td>
<td>15%</td>
<td>10%</td>
</tr>
<tr>
<td>2011/12</td>
<td>40%</td>
<td>29%</td>
<td>16%</td>
<td>16%</td>
</tr>
<tr>
<td>2012/13</td>
<td>54%</td>
<td>37%</td>
<td>18%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Source: ONS, 2014

At the start of this project, only one year of data from earlier times could be sourced from the public domain (Christopherson, 1997). In 1996/97, the excess winter deaths indices for respiratory, circulatory, and “mental disorders” (which are stipulated as being largely dementia) were:

- 2.00 for respiratory causes (in other words, twice as many deaths from respiratory causes occurred in the winter months than in the warmer months of the year)
- 1.24 for circulatory causes (24% more in winter)
- 1.37 respectively for mental disorders. (37% more in winter)

Hence, there was a 37% EWD rate among people with ADRD in 1996/97, closely approximating what ONS has reported from 2009/10 onwards.

There is no obvious explanation for these findings. By contrast, deaths from respiratory causes are higher in winter because chest and lung infections are more prevalent in colder temperatures, as are exacerbations of dangerous conditions such as COPD and asthma; influenza epidemics are also more common in winter. Similarly, deaths from cardiovascular conditions are more likely in winter because colder temperatures are associated with a risky
combination of elevated blood pressure and a thickening of the blood through the release of prothrombin. No comparable physiological reactions to cold are readily apparent for ADRD, with the exception, perhaps, of vascular dementia, in which circulatory risks may be raised as a result of cerebro-vascular change.

In 2011, ONS speculated that the effect might be attributable to a mixture of physiological and behavioural risk:

“The reasons for the seasonal pattern in deaths from dementia and Alzheimer’s disease are not clear. However, it may be related to the greater vulnerability of people with these conditions to respiratory diseases, difficulties with self-care, and falls, all of which may be more important in winter months.”

Establishing the reasons for such pronounced seasonal mortality patterns in ADRD could help inform more effective delivery of health services, as was the case for COPD when UK statistics were collated and analysed in 2006; these “helped persuade the government to announce investment in improved services for COPD sufferers” (Hansell, 2006). Understanding more about why such a marked seasonal pattern in ADRD mortality exists could contribute in meaningful ways to patient management and quality of life.

The ICD system for coding causes of death

In the UK, death certificates are completed by an attending physician, usually at the place of death. A copy is subsequently sent to a regional statistics office for entering into the UK register of deaths. Worldwide, causes of death are coded in the register according to the International Classification of Deaths (ICD) system, which was first used in 1893, and is currently in its 10th iteration. Updated versions accommodate new developments in the understanding and awareness of disease. For example, in 1960, the World Health Organization’s Mental Health Programme outlined major reforms in the coding of deaths where mental health was implicated, and these were first implemented in 1965 under ICD-8. ICD-9 was implemented from 1979. ICD-10 came in to effect in 1999 and was adopted in the UK from January 2001. ICD-10 “more closely reflects current medical knowledge”, and represents “the most radical change in the ICD for 50 years” (ONS, 2005). In the interim periods, implementation rates were often staggered and also varied across jurisdictions; in addition, refinements and bridging codes came into effect almost every year, and many researchers noted regional variations that seemed more attributable to “differences in diagnostic and clinical practice” (Hansell, 2006). As noted by Lew (1980) these revisions introduced not only different methods of classification but also some basic modifications in how certain disease groups were conceptualised. Some of these had, at
least potentially, major implications for coding ADRD as a cause of death, as will become clear shortly.

Currently, ADRD is assigned the following codes:

- F00 - dementia in Alzheimer's Disease
- F01 - vascular dementia
- F02 – dementia in other diseases classified elsewhere
- F03 – unspecified dementia
- G30 - Alzheimer's Disease

**How a single cause of death is determined:** An example of a death certificate is given in Figure 1; because these are sensitive and personal documents, the example used here is one which is widely available in the public domain.

Figure 1: Example of a death certificate (identifying elements obscured)

On Figure 1, under section 8, the left side (Cause of death: I) contains details of underlying causes; this can be divided into several sections, in this case (a) and (b). The first (a) is the underlying cause, as noted by the clinician. Details in (b) explain why (a) is thought to have happened; (c) can be used to explain why (b) had been occurring, and so on.

In this person's case, she died from a cardiovascular accident, which was the culmination of a series of repeated transient L/Ischaemic attacks. In the statistical database of English deaths,
her cause of death would have been coded as circulatory. The right hand side of Section 8 (II) details co-morbidities; these are not considered to be contributory to death, but were nevertheless present when the person died. In her case, she had also been experiencing carcinoma of the bladder and dementia; because these are listed under II, neither would have been coded as causes of her death.

When transferred to the national register of deaths, a person’s demise is assigned a single cause of death, although contributory causes and unrelated co-morbidities are also noted (see Table 2).
Table 2: Excerpt from the Northern Ireland Register of Deaths database.

<table>
<thead>
<tr>
<th>Sex</th>
<th>DODyr</th>
<th>DODMnth</th>
<th>Age</th>
<th>Place of death</th>
<th>DetailedICD10List of existing medical conditions</th>
<th>ICD10Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1990</td>
<td>4</td>
<td>25</td>
<td>NULL</td>
<td>{Y.35.0}{R.58.}{S.15.0}{S.75.0}{S.11.9}{S.71.1}{Y.35.0}</td>
<td>Y35</td>
</tr>
<tr>
<td>1</td>
<td>1994</td>
<td>7</td>
<td>89</td>
<td>NULL</td>
<td>{I.50.0}{I.18.9}{I.50.0}{F.03.0}{. . .}{. . .}{. . .}{. . .}{. . .}{. . .}</td>
<td>I50</td>
</tr>
<tr>
<td>1</td>
<td>1996</td>
<td>9</td>
<td>42</td>
<td>NULL</td>
<td>{X.95.4}{S.26.8}{S.25.0}{S.27.3}{T.14.1}{T.01.9}{X.95.4}{. . .}</td>
<td>X95</td>
</tr>
<tr>
<td>2</td>
<td>1997</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>{W.23.7.}{T.71.}{S.17.9.}{W.23.7.}{}</td>
<td>W23</td>
</tr>
<tr>
<td>1</td>
<td>1997</td>
<td>11</td>
<td>49</td>
<td>4</td>
<td>{V.49.9.}{T.07.}{V.49.9.}{}{}</td>
<td>V49</td>
</tr>
<tr>
<td>2</td>
<td>1997</td>
<td>8</td>
<td>91</td>
<td>3</td>
<td>{I.25.9.}{I.25.9.}{I.48.}{E.14.9.}{}</td>
<td>I25</td>
</tr>
<tr>
<td>1</td>
<td>1997</td>
<td>3</td>
<td>35</td>
<td>4</td>
<td>{V.02.1.}{T.07.}{F.10.9.}{}{}</td>
<td>V02</td>
</tr>
<tr>
<td>2</td>
<td>1997</td>
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<td>74</td>
<td>2</td>
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<td>I25</td>
</tr>
<tr>
<td>1</td>
<td>1997</td>
<td>6</td>
<td>34</td>
<td>4</td>
<td>{X.95.4.}{S.01.9.}{X.95.4.}{}{}</td>
<td>X95</td>
</tr>
<tr>
<td>1</td>
<td>1997</td>
<td>6</td>
<td>41</td>
<td>2</td>
<td>{Y.09.9.}{S.06.1.}{T.17.9.}{S.09.9.}{F.10.0.}</td>
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</tr>
<tr>
<td>1</td>
<td>2007</td>
<td>2</td>
<td>8</td>
<td>NULL</td>
<td>{F.03.0}{I.18.0}{F.03.0}</td>
<td>F03</td>
</tr>
</tbody>
</table>
Timeline of excess winter deaths attributed to ADRD 1991/92 to 2012/13

Table 3 provides a longer timeline on excess winter deaths attributed to ADRD than has hitherto been made available by ONS – from 1991/2 to 2012/13. It also provides this information for all 4 regions of the UK, not just for England and Wales.

From the table, it is abundantly evident that excess winter deaths associated with ADRD have been in evidence for at least the past 22 years. As a cause of excess winter deaths during a 22-year timeline, ADRD is second only to respiratory cause as the most common cause of excess winter deaths. Between 26.8% (England) and 30.7% (Northern Ireland) more deaths from ADRD occurred in winter than during the warmer months. Year on year, the annual excess winter death prevalence varied from 1.6% (Wales in 1997/8) to 95.8% (Scotland in 1992/3).

On average and taking all 4 UK regions into account, over 50% more deaths from respiratory causes happened in winter than in the warmer months; for ADRD’s, around 27% more occurred in winter; for cardiovascular causes, the figure was considerably lower, at around 18%.

Of course, many more people succumb to respiratory-cause and cardiovascular-cause deaths in winter than succumb to ADRD-cause deaths. However, the proportion of deaths where ADRD is noted as the underlying cause of death in winter is larger than the proportion where cardiovascular causes are noted, and second only to those where respiratory causes are noted.
Table 3: Percentage excess winter deaths by causes of death, 1991/92 to 2012/13, UK regions

<table>
<thead>
<tr>
<th>Time</th>
<th>Respiratory</th>
<th></th>
<th></th>
<th>ADRD</th>
<th></th>
<th></th>
<th>Circulatory</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Eng</td>
<td>Scot</td>
<td>Wales</td>
<td>NI</td>
<td>Eng</td>
<td>Scot</td>
<td>Wales</td>
<td>NI</td>
<td>Eng</td>
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<td>Wales</td>
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<td>Scot</td>
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<td>NI</td>
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<tr>
<td>1991/2</td>
<td>72.8</td>
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<td>49.4</td>
<td></td>
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<tr>
<td>1992/3</td>
<td>51.3</td>
<td>47.5</td>
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<td>95.8</td>
<td>23.9</td>
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<td>17.0</td>
<td>18.6</td>
<td>15.8</td>
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<td>1993/4</td>
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<td>53.9</td>
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<tr>
<td>2006/7</td>
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<td>38.2</td>
<td>45.5</td>
<td>33.7</td>
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<tr>
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<td>30.2</td>
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<td>61.4</td>
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<td>42.4</td>
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<td>38.4</td>
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<td>19.9</td>
<td>27.2</td>
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<tr>
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<td>33.7</td>
<td>25.6</td>
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<td>37.4</td>
<td>23.9</td>
<td>47.9</td>
<td>16.6</td>
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<td>15.4</td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2011/12</td>
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<td>30.5</td>
<td>24.2</td>
<td>17.7</td>
<td>33.3</td>
<td>17.1</td>
<td>19.1</td>
<td>32.3</td>
<td>14.3</td>
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<td>06.8</td>
<td>12.1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2012/13</td>
<td>43.7</td>
<td>34.9</td>
<td>40.2</td>
<td></td>
<td>12.3</td>
<td>26.5</td>
<td>33.2</td>
<td></td>
<td>11.8</td>
<td>14.6</td>
<td>09.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>Average</td>
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<td>49.8</td>
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<td>29.3</td>
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<td>30.7</td>
<td>17.9</td>
<td>18.0</td>
<td>12.7</td>
<td>14.2</td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>
Excess winter deaths and vascular dementia

Deaths where vascular dementia was listed as the underlying cause are of particular interest, since this condition involves constriction or occlusion of blood vessels; this could in turn lead to people being colder, especially in their extremities. In winter, therefore, they may be more likely to succumb to the impacts of colder temperatures. Table 4 compares EWD’s in Northern Ireland where vascular dementia is coded as a cause, and compares these with EWD’s for all other ADRD’s.

Table 4: Number of deaths per year where dementia was coded – all, vascular, and other

<table>
<thead>
<tr>
<th>Year</th>
<th>All Dementia</th>
<th>Vascular dementia</th>
<th>Other dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>103</td>
<td>1</td>
<td>102</td>
</tr>
<tr>
<td>1998</td>
<td>136</td>
<td>5</td>
<td>131</td>
</tr>
<tr>
<td>1999</td>
<td>168</td>
<td>3</td>
<td>165</td>
</tr>
<tr>
<td>2000</td>
<td>139</td>
<td>2</td>
<td>137</td>
</tr>
<tr>
<td>2001</td>
<td>509</td>
<td>16</td>
<td>493</td>
</tr>
<tr>
<td>2002</td>
<td>575</td>
<td>16</td>
<td>559</td>
</tr>
<tr>
<td>2003</td>
<td>508</td>
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<td>2004</td>
<td>549</td>
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<td>523</td>
<td>*</td>
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<td>2006</td>
<td>600</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2007</td>
<td>696</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2008</td>
<td>813</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2009</td>
<td>713</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2010</td>
<td>783</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2011</td>
<td>1176</td>
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<td>972</td>
</tr>
<tr>
<td>2012</td>
<td>1420</td>
<td>200</td>
<td>1220</td>
</tr>
</tbody>
</table>

*deaths from vascular dementia are not recorded during these years

Whilst it would have been reasonable to expect a preponderance of EWD’s related to vascular dementia, given the obvious association between circulatory disorders and susceptibility to cold, it appears that this particular type of ADRD shows little evidence of a winter prevalence.
Treating mortality data cautiously – ICD coding of respiratory deaths

One of the changes made in moving from ICD-9 to ICD-10 involved the coding of respiratory deaths. Table 5 provides details of how this change in coding affects deaths associated with a variety of other conditions, including mental and behavioural disorders.

Table 5: Percentage of all deaths coded to respiratory diseases in ICD-9, ranked by where reassigned by chapter of ICD-10, 1999, England and Wales.

<table>
<thead>
<tr>
<th>Reassigned to:</th>
<th>Under 75</th>
<th>75-84</th>
<th>85 and over</th>
<th>All ages</th>
</tr>
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<tbody>
<tr>
<td>Males</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory diseases</td>
<td>81.6</td>
<td>76.8</td>
<td>75.5</td>
<td>77.7</td>
</tr>
<tr>
<td>Circulatory system</td>
<td>5.4</td>
<td>8.8</td>
<td>9.6</td>
<td>8.1</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>4.1</td>
<td>4.1</td>
<td>4.3</td>
<td>4.2</td>
</tr>
<tr>
<td>Nervous system</td>
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<td>4.0</td>
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<tr>
<td>Mental and behavioural disorders</td>
<td>1.4</td>
<td>4.0</td>
<td>5.4</td>
<td>3.7</td>
</tr>
<tr>
<td>Digestive system</td>
<td>1.3</td>
<td>0.4</td>
<td>0.2</td>
<td>0.6</td>
</tr>
<tr>
<td>Musculoskeletal system</td>
<td>0.6</td>
<td>0.5</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Infectious diseases</td>
<td>0.6</td>
<td>0.3</td>
<td>0.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Endocrine, metabolic and nutritional diseases</td>
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<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Congenital malformations</td>
<td>0.6</td>
<td>0.0</td>
<td>0.0</td>
<td>0.2</td>
</tr>
<tr>
<td>Injury and poisoning</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Other chapters</td>
<td>0.2</td>
<td>0.1</td>
<td>0.3</td>
<td>0.2</td>
</tr>
<tr>
<td>All respiratory deaths in ICD-9 (number)</td>
<td>12,343</td>
<td>16,991</td>
<td>13,831</td>
<td>43,165</td>
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<td>Females</td>
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<tr>
<td>Respiratory diseases</td>
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<td>73.6</td>
<td>74.5</td>
<td>75.5</td>
</tr>
<tr>
<td>Circulatory system</td>
<td>4.7</td>
<td>9.6</td>
<td>9.8</td>
<td>8.9</td>
</tr>
<tr>
<td>Mental and behavioural disorders</td>
<td>1.5</td>
<td>5.8</td>
<td>7.2</td>
<td>5.8</td>
</tr>
<tr>
<td>Nervous system</td>
<td>4.0</td>
<td>4.4</td>
<td>3.0</td>
<td>3.6</td>
</tr>
<tr>
<td>Neoplasms</td>
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<td>3.3</td>
<td>2.3</td>
<td>2.8</td>
</tr>
<tr>
<td>Musculoskeletal system</td>
<td>1.3</td>
<td>1.8</td>
<td>1.6</td>
<td>1.6</td>
</tr>
<tr>
<td>Digestive system</td>
<td>1.2</td>
<td>0.5</td>
<td>0.3</td>
<td>0.5</td>
</tr>
<tr>
<td>Infectious diseases</td>
<td>0.6</td>
<td>0.5</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Endocrine, metabolic and nutritional diseases</td>
<td>0.4</td>
<td>0.4</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Injury and poisoning</td>
<td>0.1</td>
<td>0.2</td>
<td>0.3</td>
<td>0.2</td>
</tr>
<tr>
<td>Congenital malformations</td>
<td>0.7</td>
<td>0.0</td>
<td>0.0</td>
<td>0.1</td>
</tr>
<tr>
<td>Other chapters</td>
<td>0.3</td>
<td>0.1</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>All respiratory deaths in ICD-9 (number)</td>
<td>9,238</td>
<td>16,828</td>
<td>27,222</td>
<td>53,288</td>
</tr>
</tbody>
</table>
Based on Table 5, 3.7% of male deaths coded as respiratory in origin under ICD-9 would have been re-assigned to nervous and mental disorders under ICD-10, most of which are now coded as dementias; for females the corresponding reassignment was 5.8%.

ONS compared EWD’s recorded using ICD-9 and ICD-10 using analyses of variance and, as indicated on Table 6, found that the change in coding protocol made little difference to the overall seasonal differences in deaths related to ADRD. Instead, the change in how respiratory causes were re-assigned resulted in a non-significant change in the prevalence of many other causes, but these were not concentrated in any one or two particular causes. For the purposes of this report, therefore, ONS data concerning excess winter deaths among people living with ADRD cannot be construed as having any substantive relationship to changes in ICD coding regime.

Table 6: Excess winter death indices under ICD-9 rules (n = 10 years) and ICD-10 rules

<table>
<thead>
<tr>
<th></th>
<th>ICD-9</th>
<th>ICD-10</th>
<th>p value</th>
</tr>
</thead>
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<tr>
<td>Respiratory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>165.2</td>
<td>146.7</td>
<td>.04*</td>
</tr>
<tr>
<td>Wales</td>
<td>155.7</td>
<td>145.0</td>
<td>.24</td>
</tr>
<tr>
<td>Scotland</td>
<td>148.7</td>
<td>137.8</td>
<td>.19</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>156.1</td>
<td>134.6</td>
<td>.14</td>
</tr>
<tr>
<td>ADRD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>131.4</td>
<td>123.0</td>
<td>.47</td>
</tr>
<tr>
<td>Wales</td>
<td>129.1</td>
<td>129.6</td>
<td>.94</td>
</tr>
<tr>
<td>Scotland</td>
<td>132.6</td>
<td>129.4</td>
<td>.70</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>137.2</td>
<td>128.3</td>
<td>.49</td>
</tr>
<tr>
<td>Circulatory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>119.8</td>
<td>116.4</td>
<td>.06</td>
</tr>
<tr>
<td>Wales</td>
<td>118.4</td>
<td>117.7</td>
<td>.72</td>
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<td>Scotland</td>
<td>118.7</td>
<td>117.7</td>
<td>.07</td>
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<tr>
<td>Northern Ireland</td>
<td>118.2</td>
<td>112.8</td>
<td>.22</td>
</tr>
</tbody>
</table>

*statistically significant difference

Treating mortality data cautiously – changes in how ADRD codes are used

Many other anomalies exist in the regional UK mortality databases, and some of these pertain specifically to deaths from ADRD. Table 7 shows the correlations between excess winter prevalence scores by cause across the four UK jurisdictions, using all 22 years of data.

Correlations for respiratory cause are significant for all six pairs (range = 0.62 to 0.93), which means that the 4 jurisdictions were consistent with each other each year in assigning excess winter deaths to respiratory causes. For circulatory causes, 3 of 6 pairs were also significantly correlated indicating moderate consistency across the regions. However, only 1 pairing is significant for ADRD causes (between the 2 smallest jurisdictions, Wales and Northern Ireland); the UK jurisdictions show much greater year-on-year consistency with each other in EWD prevalence rates for respiratory and circulatory deaths, than they do for ADRD.
Table 7: Correlations between EWDi’s by cause of death across regions 1991/2 to 2012/3

<table>
<thead>
<tr>
<th>Cause</th>
<th>Wales</th>
<th>Scotland</th>
<th>NI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory</td>
<td>England</td>
<td>.93**</td>
<td>.70**</td>
</tr>
<tr>
<td></td>
<td>Wales</td>
<td>.64**</td>
<td>.83**</td>
</tr>
<tr>
<td></td>
<td>Scotland</td>
<td>.62**</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Northern Ireland</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADRD</td>
<td>England</td>
<td>-.34</td>
<td>.29</td>
</tr>
<tr>
<td></td>
<td>Wales</td>
<td>.09</td>
<td>.60**</td>
</tr>
<tr>
<td></td>
<td>Scotland</td>
<td>-.05</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Northern Ireland</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Circulatory</td>
<td>England</td>
<td>.86**</td>
<td>.32</td>
</tr>
<tr>
<td></td>
<td>Wales</td>
<td>.38</td>
<td>.03</td>
</tr>
<tr>
<td></td>
<td>Scotland</td>
<td>.65**</td>
<td></td>
</tr>
</tbody>
</table>

** statistically significant difference

Figures 2 to 4 also illustrate variations in regional coding patterns, using a standard scale on the y axis for ease of comparison. These Figures suggest that coders across jurisdictions may be slowly reaching a consensus regarding how and how often deaths from ADRD are coded, but this has been a relatively slow process.

Further exploration of how ADRD’s are distributed across the 2 main codes for ADRD deaths reveals more regional anomalies (see Figure 5). Northern Ireland shows a steady decrease in the proportion of EWD’s attributed to Alzheimer’s Disease, whilst Scotland has shown an equally steady increase; England & Wales have remained relatively stable in assigning these 2 primary ADRD codes across time.
Figure 2: Percentage of excess winter deaths: respiratory causes

Figure 3: Percentage of excess winter deaths: circulatory causes
Figure 4: Percentage of excess winter deaths: dementia and Alzheimer’s Disease

Figure 5: Deaths attributed to dementia and AD: percentage attributed to AD
Brief summary of results

These data convincingly establish the extent to which excess winter deaths attributed to ADRD are a longstanding phenomenon, an important finding in its own right. Beyond that, however, they raise more questions than they answer. They highlight a wide range of anomalies in how ADRD deaths are coded in different jurisdictions, and for that reason, it is difficult to establish any robust explanations for why ADRD exhibits such an elevated excess winter death rate.
Section 2

Insights from carers

“We will carry out informal focus groups among carers who look after people living with AD and dementia, so that we can better understand the extent to which home heating and energy efficiency routines become problematic for people still living independently with these illnesses.”

Introduction

In a 2013 Report, the Department of Health stated:

“Timely diagnosis of dementia really matters. It is the key to helping people with dementia, their families and carers get the support they need, to plan for the future and to make informed choices about how they would like to be cared for. We know that with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.”

Recent research involving patient participation within one metropolitan area (Chrisp et al., 2011) shows that there are two key stages of delay in diagnosis – firstly, the period (on average one year) between noticing something amiss and mentioning it to a friend or family member and secondly, the period (a mean gap of 1.3 years) between mentioning it to a friend or family member and first contact with a healthcare professional. There may be a third period of delay until a diagnosis is made. In general Chrisp and colleagues report a period of around three years from a person thinking there was something amiss to them arriving at a health facility for a formal diagnosis. In a further study Chrisp and colleagues (2013) note that in only two of 20 cases did the person with symptoms initiate engagement with healthcare professionals. Family members and carers were most often the first to take action.

It is widely agreed that the goal of dementia care is primarily to keep people as well as possible, and for as long as possible in their own homes, provided that is where they prefer to be (DSDC, 2012). Whilst at home, care is more likely than not to fall on families when dealing with day-to-day needs, including housework, grocery shopping, cooking and assistance with finances.

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3 Excerpt from grant proposal submitted to the Chesshire Lehmann Foundation
In this Section we explore insights from people with ADRD who live at home, and the people who help care for them. We focus on issues related to thermal comfort, home heating and energy efficiency.

The participants consist of an informal focus group of professional carers, and six one-to-one interviews with family carers. With the consent of participants, these were all taped and transcribed for the purposes of analysis.

Some of the people that participants care for have been diagnosed with Alzheimer’s and others with vascular dementia. None were diagnosed with early onset dementia and the earliest known age at diagnosis was early to mid-70s. The majority still live in their own home, but one lives independently in sheltered accommodation and one lives independently in accommodation especially designed for people with dementia. They are at different stages of dementia, but all are still able to be reasonably active and can manage daily care and activities with assistance. One of the people with vascular dementia had previously cared for her mother who had Alzheimer’s.

**Home heating, ordering fuel and payment of bills**

All of the carers helped look after people in homes which have central heating systems, although not all radiators have thermostats, meaning that either all rooms or none are heated at a time; not all have heating in the bathroom. Heating sources are oil, gas and Economy 7, and some having additional electric fires; there is underfloor heating in the specially designed accommodation. Several of the people would have grown up with an open fire in their home, rather than central heating, so would have been used to draughts and cooler temperatures in parts of their home.

Before the onset of dementia, people being looked after had kept their homes as warm as possible:

> "While they were always very aware of the cost of being warm and comfortable, they always put a store on having a warm and welcoming home."

They had previously been very capable of operating their home heating systems, and had been diligent about regular boiler servicing and maintenance. The onset of dementia has meant that carers

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4 The family carers who assisted us all expressed a preference for a one-to-one conversation in their own homes, since they were uncomfortable about sharing experiences in the presence of other family carers who they did not know; our only focus group was, therefore, with professional carers.

5 The normal setting of the system is 22°C with +/- 3 degrees. Each flat has a thermostat allowing 3 degrees of adjustment.
Carers mentioned that ability to use money and pay bills had changed:

- “Paying bills would be difficult, very difficult.”
- “We were kind of worried about how vulnerable he might be with his money and that because you know he would tend to tip people a lot.”
- “It’s all changed on every level since having the stroke.”
- “When she was fit and well she would have been the one in the house would have paid all the bills.”

This, in turn had led to tenants receiving more correspondence from their utility companies:

- “… and they’ll send you another bill, send you another bill, send you another bill, then they’ll threaten you with legal action, and this person doesn’t know to pay the bill.”

Another potential problem is that the person with dementia may not realise that the heating is not functioning properly:

- “If it wasn’t working right they mightn’t know and that could be, again, cause of crisis.”
- “There was a power cut and she had no heating and she hadn’t a clue how to fix the clock on it… so she had no heating in the morning.”

One tenant was in the habit of switching everything, including the heating system, off at night, meaning she got up to a cold home in the morning, with no hot water. The carer has had to take further measures to prevent this:

- “So then they put a lock on the door, a lock on the hot press so she can’t open the door.”

Immobility might have been a risk for some, since carers remarked that tenants often stayed longer in bed in the mornings than they have in previous years, particularly in the winter months.
Turning sources of heat off and on could also be hazardous:

“...we noticed... he had 3 fairly deep cuts in his head ... I was thinking he's hit his head on the corner, I couldn't think what it was... it suddenly dawned on me it was the fireplace. When he was leaning forward to turn the fire on...He had no recollection of how he had done it...Thankfully he seems to heal up pretty quick.”

**Energy efficiency and cost**

Many of the tenants had been energy-conscious in their earlier years:

- “She would have considered heating expensive and you know heated to the bare minimum.”
- “She was always great with numbers so she would have known how much was going out, how much being spent on fuel, whether it was good value or not.”
- “She might have said “Do you think that heat could go off?”, but I think that was more conscious of the cost.”

On the other hand, carers now gave priority to a reliable fuel service despite any additional cost, and preferred to keep to the same known and trusted supplier rather than seeking the best price:

- “It’s probably cheaper for him to heat the whole house with the oil to be honest rather than using the electric fire.”
- “I wouldn't want any stranger coming to the house...Which might be one of the reasons why people stick to the same supplier, because you have to get round the back to fill the oil tank.”

Whilst carers frequently put heating on when they arrive at the tenant's home, there is the additional problem of the person switching off the heating when they leave:

“You can bet when you leave that my daddy notices again that the heating has been switched on and he’ll probably turn it off. I think he's probably more worried about the cost of it. Even though the cost has never really been an issue for him, but it's in his head.”

There is also a need for lighting the home well, although in some cases, people with dementia tended to keep lights on constantly. This may reflect the sundown effect reported in the scientific literature, whereby people with ADRD become more anxious and distressed when it becomes dark (Joseph et al., 2013):

“...but now the lights are never off... all lights are blazing so you don’t even know if she's in bed or not.”
Carer awareness of grant schemes for heating and insulation

Not all carers were aware of schemes for heating and insulation, but cavity wall and loft insulation had been installed in a few of the homes through the Warm Homes scheme. In one case, the carer’s home had benefited from the scheme, which led to applying for installation in the home of the person cared for:

“That kind of triggered ‘well I must go and see what we can get done in Daddy’s and get that done so’.”

One tenant, living in a privately rented house, had encountered difficulties with the landlord and the family preferred to pay for the improvements themselves:

“They had a very difficult person to deal with in terms of the owner of the place. Any improvements that they had done to the house, me and my dad had paid for, because the hoops she would have made him jump through to do anything simply wasn’t worth it.”

Dressing appropriately for weather conditions

If the person with dementia is going outdoors, carers are concerned that they need to wear appropriate seasonal clothing and would remind them in person or by telephone.

- “Without that, I wouldn’t be sure that he would be putting his coat and all on him all the time.”
- “She doesn’t realise how cold it is outside when you’re used to this environment [being warm indoors].”
- “We would make sure she had a scarf and gloves and things.”

Many families also need to leave out clothes for the person to wear and have bought thermal socks and underwear in an attempt to help:

- “I think men especially, they've thin trousers on, maybe, and their legs are cold.”
- “Mummy would dress herself and my daddy [himself showing early signs of dementia] never really noticed that she was wearing inappropriate clothing for the weather.”
- “She would have been dressed in quite skimpy more summer clothes.”
- “She pretty much dressed the same all year round.”
- “We hunted all these things out for him and left them sitting and I bought him gloves. He still doesn’t wear the gloves, he won’t wear the gloves, and I think he'd probably leave them behind somewhere anyway, but he’s managed to hold onto the hat.”
Clothing may become an increasing challenge as dementia progresses:

- She doesn’t dress. She wears the same clothes day in day out, until you go and take them off.
- “She would have chosen what she wanted to wear, but we would have gone in and you know said “You need something warmer on you” or I’m not sure if you know we might have advised her to take something off as well you know “It’s roasting, Mum, take that coat off.”
- “He’ll just wear what he’s wearing, so I’ve never seen him putting on extra or thicker clothing or anything, never seen him do that.”

These comments point to the likelihood that sensitivity to both heat and cold may be simultaneously impaired, at least for some people living with ADRD.

**Awareness of temperature indoors**

People with dementia may not always dress appropriately for the weather, but they may also be unaware of how to maintain a comfortable temperature within the home:

- “You know he’s definitely cold, but he’ll say “oh no, no, I’m fine”.”
- “Funny enough whenever Mummy was alive, Daddy was so fussy about making sure that the heating was on for Mummy.”

Some people realise that they are feeling cold, but do not seem to know what to do about it:

- “She wouldn’t think to say “Oh I’m feeling cold, will you turn up the radiators?”.”
- “Fleecy blanket on the chair beside her, she wouldn’t think I’ll lift that and put it on me and that might make be warmer. That connection is just not there at all...So if you put a note in front of her to say ‘if cold there’s a blanket’, she’d read the words but she wouldn’t reach for the blanket.”
- “She’s aware when she’s cold. Certainly, before now I think she would, if prompted, she would have known to turn up her radiator and unprompted she would know to turn it down if she got too hot.”
- “She wouldn’t make any connection between feeling cold and needing to put something on.”
- “She may have had problems with the temperature, was she feeling hot/cold.”

This is understandably of great concern to their carers:
Collectively, the carer accounts showed that people with ADRD, and more so as the illness progresses, have difficulties associated with both heat and cold:

- “If she didn’t have the carers going in or us going in, she would just sit and get very cold and really get into difficulty.”
- “I would worry that if no one was there that I think he would keep himself warm in the living room, I do think he would still put on the electric fire and stuff, but I think the rest of the house might end up being very cold.”

For some there may be a connection between warmth and a general feeling of comfort or security while others may prefer less heat for comfort:

- “But she definitely, she makes comments about the weather.”
- “Well they find it difficult to keep warm and especially in the severe temperatures.”
- “I think even if you took the temperature up she would she would still not feel...I don’t think she’ll ever get to a point where she’ll be too warm.”
- “The living room was rarely ever closed and now the living room door is closed and the bars [electric fire] are on. He must be feeling it, that he’s having to put it on.”
- “Some of the carers say it’s far too warm in her house.”
- “We would have gone in and said “Gosh, it’s cold in there, are you not cold?” and she would have put her coat on.”
- “...sometimes he wouldn’t have the heaviest blanket on his bed...he doesn’t like a lot of weight on him...He just has the ordinary duvet but we do try and make sure he has an extra blanket, a warmer duvet.”

A theme that emerged consistently from carers was their difficulty in knowing how much heat the person really wants, rather than needs, and some people who have been used to less heating in past years may not think to use it now when it is available to them:
Keeping warm and weight loss

A new phenomenon, referred to as "the anorexia of ageing" has recently been noted by researchers (e.g. Herke et al., 2015). It is not specific to people living with ADRD, but is particularly likely among this group, especially when they are living independently. Most of our carers reported a lack of appetite among people with dementia and the need to remind them to eat. They gave us a wide variety of insights into the myriad reasons for them eating less and losing weight.

Those who were still able to prepare food, tended to make a light snack. Similarly, the ability to use kitchen appliances varied. Some people could still use a kettle, a microwave and a toaster, while others needed assistance:

- “In fairness, my father never did feel the cold, but there’s times that I’ve gone in and his hands are cold.”
- “Most of her married life she lived in a draughty old house where there was only like an Aga, like a Rayburn. There was no central heating in the building.”

Carers noted that as dementia progresses, the ability to prepare meals and use kitchen appliances would appear to wane:

- “She doesn’t eat all that much now.”
- “He doesn’t seem to feel hungry.”
- “She would tend to maybe not feel hungry, she needs prompted to be reminded to eat.”
- “He would maybe make a cup of tea and have a couple of biscuits, digestive biscuits were his favourite but that’s not enough to be living on.”
- “She liked that you could make soup in a cup you know, and 20 years ago she would have thrown you out of the kitchen for the very suggestion.”
- “The big meal at lunch time is very filling and she doesn’t need that much.”
- “We’d leave him a bottle of Shloer and his glass out to try and encourage him to drink because that’s another worry, that he wasn’t getting enough and he was getting dehydrated.”
- “…we put a notice board up in the kitchen so that if any of us call in, we write that we called, and what he ate, if he ate anything.”
- “you could see she was eating a lot of bread and biscuits and things that she could just have with a cup of tea.”
In one case, a toaster was removed for safety:

> “On the toaster she lit paper and lit her cigarettes.”

Another issue raised regarding food preparation was not knowing that it was a mealtime:

> “She didn’t know when to make her dinner, she didn’t know when to make breakfast, she didn’t know the time of the day.”

The buying of food was routinely done by the carers, which helps to ensure as far as possible that the right amount of food is available:

- “She might have had four loaves of bread in her fridge and far too much milk and loads of butter and, you know, she wouldn’t have had staples, you know, she wouldn’t have had fruit or vegetables or whatever.”
- “She used to waste a lot of food.”
- “I was finding that I was throwing out an awful lot of stuff because like ready meals for one person are just too big for her and also often they were not the kind of thing she wanted to eat.”
- “We buy that pack of mixed cereal so she’s not eating cornflakes every morning.”

Carers assist with meal preparation as much as possible by leaving frozen foods and reminders, but with varying success:
Carers also commented on the positive effect of variety at mealtimes, such as having company or being involved in food preparation:

- “I could leave him a dinner with cling film over it and I’d put a note on the top of it, ‘Daddy, put this in the microwave for 3 minutes’ and I’ll set the microwave for 3 minutes and he literally has to put it in and close the door and it automatically starts, so he can manage that.”
- “She had a habit of, when frozen meals were in her own freezer, taking them out and defrosting them, so we stopped that.”
- “The carers took the dinners out and left them on the top. She would have eaten them raw. Not raw, no they’re not raw, they’re cooked but frozen, she would eat that.”

Some of the carers mentioned weight loss specifically:

- “Now because he’s just got himself, our worry is that he wasn’t eating enough.”
- “We took her out for an Indian, it was her birthday, and she wolfed it down because it was different and it was spicy and she was out, and it wasn’t far from where she was living, she only had to walk a couple of minutes to get there.”
- “…she ate more in that lunch than she would generally be inclined to do and I think part of it was because she had been involved in the food preparation and she was engaging with what was going on, rather than somebody round the corner going ‘ding and here’s your dinner’.”

As seen with heating, these tendencies and preferences may have little to do with the onset of ADRD, and so it is difficult to be certain how much might be attributable to longstanding eating habits, or to the ageing process per se:

- “My father always ate like a bird anyway, I mean he was never a big eater.”
Use of other household appliances and technologies

Over and above kitchen appliances, the ability to use other gadgets and appliances varied, but carers were aware of the capabilities of those with dementia. Some were unable to switch on a television or radio. Others were able to answer the telephone, but no longer made outgoing calls:

- “She can use a telephone but I haven’t heard her on the phone, not in years.”
- “She left the phone off the hook.”

This can make the use of emergency equipment difficult:

- “She was pressing it [emergency button] non-stop.”
- “…the one they wear around the neck, I mean she’d have taken it off and left it down... However that wouldn’t have been much good to her if she had fallen.”
- “That’s absolutely no benefit to that woman because she doesn’t understand it. The phone bit is still there but she doesn’t understand.”
- “She wouldn’t make any connection between the, ‘there’s an emergency cord’ and ‘I’m in a difficult position here’.”

Where people with ADRD are unable to alert their carers to being cold, even in situations where they are aware that the discomfort they feel is cold-related, they may be at home for long periods of time without remedy.

Carer awareness of assistive technology

Assistive technology related to housing and thermal safety includes monitors for identifying extreme high or low temperatures. Increasing lighting to double the normal amount has also been shown to be beneficial for people with dementia (DSDC, 2013). Other aspects of increasing age and frailty include sight impairments, which may also prevent people with dementia being able to adjust their home heating controls or use kitchen appliances to prepare meals safely. Larger displays coloured buttons and voice-activated controls are all useful measures for alleviating these problems for some people. However, none of these and many other possible devices for helping people with ADRD live at home for longer were known to the carers we spoke to.
Routine

Heating regimes in cool temperate climates (such as prevail in the UK) are seldom able to be fully automated because heating need can vary greatly from day to day (Liddell & Morris, 2015). As a result, they need either frequent non-routine adjustment or temperature-sensitive controls. For people that rely on routine for their general wellbeing, this makes the regulation of heating a challenge. In this context, the importance of routine was mentioned by some carers, with one remarking that her father is still aware that he used to do something at a particular time. The familiarity of the routine may provide comfort:

- "She was very keen to have a routine of always having a bath before bed [and now has to get used to a shower instead]."
- "It’s routine usually with dementia, it’s getting their routine and she likes to know what she’s doing all the time so if it’s written down, it happens, it’s going to happen. If it doesn’t get written down it’s forgotten about."
- "We took her to church on Christmas Day, we took her to mass over the road and again she finds a great deal of comfort in the familiarity of that kind of thing."
- "They don’t like change at all, but fair enough you know."
- "But if some of the carers tell her it’s Sunday she’ll say to me ‘I should have been at Mass’."

Hospital was also a particular challenge to routines. Carers spoke of the confusion and discomfort of those they cared for when in hospital. Although they were well cared for, the change of environment and routine upset them. In addition, their house may not be cared for, or heated, while they are in hospital:

- "After she came out of hospital she couldn’t take any noise, the noise of the television, the noise of the phone."
- "For most of the time when she was in hospital she was in a little room on her own but that in itself brought all sorts of difficulties because she really had no idea where she was and even with the blank walls there was nothing to give her any clues."
- "When he was in hospital I went over to the house and the house was really cold you know and the heating wasn’t on."
**Change in condition**

As noted at the start of this section, timely diagnosis can matter greatly to the management of ADRD. Carers were able to look back and see that there were early signs which seemed insignificant at the time. Then, as the dementia has progressed, there have been more noticeable changes:

- “Small signs, but only in retrospect, it’s just when you saw situations when she couldn’t have coped, you know, thought there was something wrong.”
- “The amount of mail that had accumulated over a 3 year period, you couldn’t have seen the floor.”
- “…and you thought he was coping all right.”
- “She has sort of stock responses you know that she’s kind of developed over the years, either in a social situation where she might not be entirely sure who she’s talking to.”

From the carer accounts, it seems possible that some of the most basic living routines of eating and heating a home may deteriorate rather early on. However, triggers that initiate a search for diagnoses are often associated with more bizarre and flamboyant behaviours, rather than with lapses in these more mundane daily practices.

**Memory**

Carers reported that those they cared for often could not remember that family members from earlier generations have passed away, or that they are no longer living in their childhood home:

- “She’s always wanting to go home, that was their home years ago over there.”
- “Back to childhood and ‘this is not my home’ and ‘my coat and everything is over in that other house. Where’s my piano?’”
- “She’s always looking for her mummy and ‘where’s my daddy?’”
- “She had been found looking for my father who had died 20 years earlier.”

One of the volunteer groups who joined the focus group uses their morning telephone calls to remind people what day it is and to take their prescribed medication for that day. However, this is in itself a concern with some of the people:

- “I’m always a wee bit wary of that in case you remind them to take medication and they’ve already taken it, you’re telling them to take it again.”
- “They had to lock her medication because she was overdosing.”
It goes without saying that heating regimes require a complex set of executive functions, medium-term memory skills, and an instrumental recall of what behaviours will remedy any malfunctions or adjustment needs.

They also reported that one person constantly telephones them to return their call:

“That could go on for 6 or 7 times in the afternoon.”

**Physical health**

Many of the people with dementia were physically fairly healthy for their age.

- “There she is, as healthy as can be.”
- "Despite her mental state, she physically was in great shape, you know, I mean she could practically run... she could have walked the legs off you."

However, in several cases, carers were dealing with health conditions in addition to dementia. These included:

- Raynaud’s syndrome
- Stroke
- Heart surgery
- Aneurism
- Fluid in the lung
- Chest infection
- Depression
- Grief
- Falls and accidents in the home

In some cases, these would have had an impact on the body temperature and mobility of the person being cared for:

- “Mummy had Raynaud syndrome as well, so she would have felt the cold... she had hot cups of tea to wrap her hands around to thaw her fingers out...”
- “Her circumstances have changed now, she had a wee fall and we don’t really know why the reason was, but since that she hasn’t been as mobile as she used to be...”
Summary

Among the carers we spoke to, none of the people they looked after were responsible any longer for the programming of heat in their home, or the ordering of fuel or the paying of energy bills. Those with gas heating did not have to remember to order fuel, but family members still had to pay the bills; those with oil relied on family to order and pay for fuel, and those living in sheltered accommodation had the fuel cost included in their overall charges, something which one family carer described as “…going into sheltered accommodation with central heating has been a luxury for her”.

Concern was expressed about dressing appropriately for weather conditions, and not adding another layer when feeling cold. There was not always a connection made between feeling cold and putting on more clothing. Several carers remarked that the homes were either very hot or quite cold, with the person switching off the heating when carers were not there. Circumstances such as a power cut or malfunction of the heating system could not be dealt with by the person with dementia. In addition, other health conditions such as heart problems, stroke and Raynaud’s syndrome affected the level of heating required for comfort. Some people were inclined to stay longer in bed to keep warm, particularly during the winter months, and this as well as low mood, and fear of accidents or falling led to significant reductions in mobility for some.

Energy efficient measures which carers might have considered, such as converting to gas, or shopping around for the best fuel price, were overshadowed by the need for the safety of a known fuel supplier calling at the house and not disrupting the house with heating conversion.

There was concern about the ability to prepare meals and eat adequately, and carers noted how assisting with food preparation and having company at mealtimes encouraged eating. There was also the issue of not knowing when it was a usual mealtime, given the loss of a sense of time among some. While several people with dementia could still tell the time, they were unaware of it being day or night, particularly in darker days of winter. As a result of these and many other problems around preparing and eating food, several people had suffered weight loss according to their carers, with probable effects on their ability to keep warm.

Outings and social interaction were seen to have a beneficial effect on people with dementia, many of whom had been very active and enjoyed various activities and interests pre-diagnosis. Despite enjoying variety, they also appreciated routine, and it is likely that variable time spent in hospital could be upsetting. Returning home from hospital required another readjustment, and homes were often untended and unheated in the interim.

There was a noted lessening of ability to use the telephone and use of household appliances and technology, including the telephone, varied among people with different levels of dementia, but was
frequently unreliable. Several carers left reminder notes, but, while these were useful for some people, in other homes the note would be read but not acted upon.

None of the carers we spoke to were aware of their right to register the person they cared for on a Priority Service Register, which all utility providers are required to maintain by law. Many carers were also unaware of grant schemes for heating and insulation, which would help the energy efficiency of the home and help to reduce fuel bills, thus relieving financial concerns. They also had little or no access to information on assistive technologies which could have enhanced the daily living conditions and wellbeing of those they looked after.
Section 3
Synthesis

“The results will provide an informed perspective on which to establish whether there are realistic ways in which treatment and prevention issues merit consideration, in order to lower the number of EWDs that arise from this particular cause of death, especially among the fuel poor; and also in order to develop a better protocol for looking after people who are living independently with AD and dementia, so that they have more protection from falling into, or deepening, their exposure to fuel poverty and its effects.”

Introduction

Older people, regardless of their mental state, are known to be more vulnerable to cold environments through a mixture of biological and behavioural reasons. The physiological explanation is that older bodies are less effective than younger ones at maintaining their core body temperature when exposed to cold stress. Older bodies experience a lower metabolic rate, thus lower heat production, and a less effective vasoconstriction response, rendering them less able to divert blood away from the skin (DeGroot and Kenney, 2007). Other contributory factors include low body fat through weight loss, sedentary lifestyle, medication use and chronic conditions, including heart conditions, circulatory disease & diabetes (Marmot Review Team, 2011). Additionally failing faculties, such as vision and eye-hand coordination, make managing heating controls and boiler systems more difficult than they are for younger people.

However, the specific reasons for an association between cold, mortality risk and people living with ADRD are less well understood. The scientific literature related to this topic is:

- sparse
- methodologically patchy
- largely anecdotal
- a-theoretical in nature.

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6 Excerpt from grant proposal submitted to Chesshire Lehmann Foundation
Biomedical contributors: The debility cascade

Jones and Goldeck (2014) offer the most comprehensive account of potential biomedical routes by which living with ADRD may increase risk of winter mortality (see Figure 6). They describe these risks as seemingly "chaotic", but they are able to organise them into a systemic pathway, in which a diverse set of risk factors can, potentially, increase frailty exponentially as risks accumulate.

Ageing, they hypothesise, is associated with increasing genetic aberrations, and hence greater vulnerability to viral infections. They emphasise particularly a triggering role for "the ubiquitous herpes cytomegalovirus" which – they speculate – lowers people's resistance to a variety of other infectious agents (particularly those of a respiratory nature), and simultaneously contributes to cognitive impairment. Viral infections, in turn, create inflammatory reactions and antigenic stress, as well as a loss of appetite and concomitant malnutrition (or more likely in many cases under-nutrition). Treatment regimes associated with GP and hospital consultations may do little to slow neurogenerative processes, and may lead to increased confusion; this too is exacerbated as people become increasingly frail. Immobility whilst unwell results in a lack of exposure to sunlight, and hence vitamin D deficiency (long associated with neurogenerative disorders); immobility also contributes to poorer lymphatic flow and muscle wastage, which further weaken people's immune systems. A second viral infection becomes more likely, particularly in periods of cold weather when viruses circulate more frequently, and this can lead to secondary complications such as pneumonia. Another hospital admission can either mean people enter another cycle of risk, or succumb altogether.

It is perhaps apt that Jones and Goldeck's work was published in the journal Medical Hypotheses, since most of the routes to poor outcomes which they depict in Figure 6 remain speculative. The figure is, however, a very valuable heuristic.
Figure 6: The debility cascade in neurological and degenerative disease (Jones & Goldeck, 2014)

- Ageing
- Genetic impairments
- Viral infection(s)
- Inflammation
- Antigenic stress
- Malnutrition
- ↑ GP visits
- Neurodegenerative
- Increased weakness and confusion
- Homebound/institutionalized/immobile
- Lack of sunlight
- Poor lymphatic flow
- Lack of vitamin D
- Muscle wastage
- Outbreak of any infectious agent
- Secondary complications (mainly pneumonia)
- Increased in- and outpatients admissions
- Eventual death
Thermal insensitivity may be to heat as well as cold

Carers’ reports reminded us that sensitivity to cold is very likely to be only one aspect of temperature vulnerability in people living with ADRD, since heat-related excess deaths are also common. Heatwaves have been found to be associated with an 8% excess for AD and a 6% excess for dementia in large-scale epidemiological research (e.g. Zanobetti et al., 2013). An inability to perceive both heat and cold accurately is also supported by anecdotal evidence that people living with ADRD are as likely to heat their homes to higher than average temperatures as they are to lower than average temperatures (van Hoof et al., 2010). It is not so much that cold is a problem for people living with ADRD, but rather a variety of deviations from what they perceive to be normal temperatures.

Are people cold or just feeling cold?

In this context, it remains unclear whether disturbances in temperature regulation are:

- physiological in origin
- related to disturbances in sensory perception of heat and cold
- or a variable combination of both.

There are rational grounds for assuming that physiological processes around thermoregulation will commonly be implicated. For example, Satlin et al. (1995) found a delay in the time taken for core-body temperature to adjust among people living with ADRD, suggesting a potential lag or inability to acclimatise effectively. Klegeris et al. (2006) describe how circulating cytokines are thought to affect the preoptic-anterior hypothalamic area, which in turn affect cyclooxygenase and prostaglandin levels; together, they speculate, these could result in a shift in the set point of core body temperature. Similarly, Holtzman and Simon (1999) describe the process of beta amaloyid proteins collecting at nerve endings, which could in turn affect thermoregulation. However, a meta-analysis of 6 studies comparing core body temperature among people living with ADRD and matched controls concluded that the difference in body temperature between ADRD and control groups was negligible, at around 0.1°C (Klegeris et al., 2006).

In terms of disturbances in sensory perception, Bakker (2003) speculated that people living with ADRD may perceive temperature differently, since impairments of sensory perception are known to be associated with disabilities such as aphasia, apraxia, agnosia and amnesia – all of
which are common among people living with ADRD. These disabilities might lead to a combined risk of impaired ability to perceive cold and difficulty in expressing thermal discomfort.

A recent Swedish study notes that, whilst hospital admissions for accidental hypothermia are most commonly associated with ischaemic heart disease, the second-most common cause is dementia (Brandström et al., 2014). Frostbite and hypothermia among people living with ADRD occur most commonly as a result of going outdoors inappropriately dressed for outdoor temperatures. Several of our carers mentioned the tendency of those they looked after to dress inappropriately for the prevailing temperatures, and this applied both indoors and outdoors.

A difficulty in establishing whether people have become insensitive to cold as a result of living with ADRD is that we have no measures of their thermal sensitivity before the onset of their disease. Carers often remarked on the fact that the person they looked after had always felt cold to the touch but had never complained; difficulties people with ADRD have in communicating about what they feel make this especially difficult to disentangle. However, the sheer prevalence of excess winter deaths in this group does point most strongly to the likelihood that people with ADRD are living with levels of cold that exceed what can reasonably be considered as within a normal thermal range. Whether this is because disturbed physiological processes mean they cannot get warm in cold conditions or cool down in heat, or because their sensory perceptions are disturbed, it remains the case that their exposure to temperatures outside the normal range make them significantly more vulnerable than they would otherwise be.

**Treatment regimes and thermal sensitivity**

Both Brandström et al., (2014) and Rocklöv et al., (2014) note the association between treatment with psychotropic drugs and risk of both hypothermia and frostbite – psychotropic drugs are commonly used in the treatment of ADRD, particularly in cases where severe mood disturbances and aggressive episodes are problematic for people’s own wellbeing and that of their carers. Page et al. (2012) note some of the drug regime pathways by which an impairment in temperature sensitivity may come about:

"Mechanisms probably vary depending on the medication. Antipsychotics may alter the temperature regulation set point via anti-dopaminergic action...opiates may interfere with responses to temperature via skin vasculature".

As will be seen, carers did not seem aware of this possible link between thermal sensitivity and drug regimes, although one carer noted how withdrawing treatment seemed to improve the demeanour and wellbeing of the person they looked after.
Darkness and mood

As is also common for people sound in both mind and body, longer and darker nights are thought to have an impact on the general wellbeing of people with ADRD. Anecdotal evidence of this derives from interviews reported by Joseph et al. (2013), who describe the so-called “sundown effect” - increased restlessness and distress after darkness has fallen. Whilst this was not noted among the carers we interviewed, many remarked on confusion between day and night, especially in the darker months of the year. Innovative lighting technologies which can mimic daylight may have an important role to play in helping people with ADRD regulate their daily routines better.

Social isolation

Social isolation, which is likely to increase as the symptoms of ADRD progress, have been reported in other studies as causing an increased risk of exposure to cold among people with ADRD (Dawson, 1987, Gilmour et al., 2003, Holtzman & Simon, 2000). Several of our carers mentioned that heating was being used in unusual ways when they arrived at the home of the person they were looking after – temperatures were too high on some occasions, too low on others, and heating was sometimes turned off altogether.

Social isolation may also exacerbate risk less directly, through people eating less during long periods alone (Herke et al., 2015). We did not probe around alcohol intake, but it is possible that social isolation will exacerbate this, which in turn is known to have a measurable effect on heat loss and sensitivity to cold.

Managing home heating and payment of fuel bills were clearly a set of skills which people living with ADRD lost capacity for early on, and unanimously. Our carers all agreed that heating and payment of fuel bills had to be taken over by family members, with common problems being not remembering to order fuel, no longer being able to manage to adjust heating controls, and being unable to understand the instrumental link between feeling cold and putting on layers of clothing. Carers therefore needed to assume responsibility for ensuring that appropriate clothes were being worn to suit the indoor temperature and the outdoor weather. Other illnesses which those they cared for suffered, in addition to ADRD, often required a warmer home temperature for comfort.

Although carers realise that conversion to other forms of heating may be more energy efficient, they are reluctant to cause distress to the person with dementia through disruption during installation work. The sound rationale behind this is evident from other areas of their accounts, which describe
people’s love of routine, the ease with which these routines can become disrupted, and the consternation that this can create. For similar reasons, carers prefer to buy from the same oil supplier, rather than have an unknown supplier make a delivery, albeit more competitively priced.

Augmenting the cascade approach of Jones and Goldeck, which focuses largely on biomedical pathways to risk, we have summarised the additional learning gleaned from the carers who have helped us with this research, and this is illustrated on Figure 7.
Figure 7: What carers told us: possible pathways contributing to excess winter deaths associated with ADRD

- ADRD and susceptibility to cold
  - Sight impairment
  - Accidents in the home
  - Psychotropic drugs
  - Low levels of physical activity
  - Thermal insensitivity
  - Loss of sensory perception of cold
  - Forget to buy energy/fuel
  - Managing energy systems
  - Inappropriately dressed for the indoor temperature/outdoor weather
  - Financial status and fear of cost
  - Alcohol
  - Eating habits and weight loss
  - Social isolation
  - Financial status and fear of cost
  - Timely diagnosis
  - Loss of sensory perception of cold
  - Forget to buy energy/fuel
  - Managing energy systems
  - Inappropriately dressed for the indoor temperature/outdoor weather
  - Financial status and fear of cost
  - Alcohol
  - Eating habits and weight loss
  - Social isolation
  - Timely diagnosis
  - Low levels of physical activity
  - Thermal insensitivity
  - Loss of sensory perception of cold
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  - Timely diagnosis
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  - Social isolation
  - Timely diagnosis
  - Low levels of physical activity
  - Thermal insensitivity
  - Loss of sensory perception of cold
  - Forget to buy energy/fuel
  - Managing energy systems
  - Inappropriately dressed for the indoor temperature/outdoor weather
  - Financial status and fear of cost
  - Alcohol
  - Eating habits and weight loss
  - Social isolation
  - Timely diagnosis
Summary

From Section 1, it is evident that excess winter deaths associated with ADRD as the primary cause of death are a long-standing and intransigent phenomenon. Whilst EWD’s related to respiratory and cardiovascular causes have long been researched and disseminated, this is the first research study to demonstrate a convincing need to begin doing the same for EWD’s related to ADRD.

In this context, we contacted all the major UK support and research agencies concerned with ADRD, outlining the prevalence of EWD among their client group, and asking for their insights on this issue. We did this twice. None replied.

We also scanned the literature and web pages of these agencies for information on the risks of EWD’s and how to ameliorate these. We found none. Many of these agencies suggest that focus needs to be on Cause, Cure and Care for people with ADRD. It is questionable whether as much investment is being made in the field of Care as in identifying the causes and treatment. There are gaps in all 3 domains, but those related to Care are surely the more readily remedied.

Much of what has been learned from Section 2 confirms Jones and Goldeck’s (2014) debility cascade, joining a variety of anecdotal accounts about how winter adds an additional layer of risk to many other aspects of vulnerability for people with ADRD. What is clear from this Section is the myriad small but inter-related risk factors that people with ADRD encounter when temperatures fall below the more clement months of late spring, summer, and early autumn. This is consistent with cumulative stress theory (first posited by Rutter and colleagues in 1975), which asserts that vulnerability increases quadratically (rather than in a linear fashion) when people experience an accumulation of stressors from multiple sources. A quadratic effect is found when one stressor is added to another but does not simply double the risk of maladjustment – instead risk increases four-fold; adding a third stressor can increase risk ten-fold rather than simply tripling it. Many psychological studies (though not linked to excess winter deaths) have corroborated this concept.

Reviewing progress since the 1970’s, Thoits states:

“..mounting evidence revealed that cumulative stress exposure explained far more variance in...distress and disorder than investigators initially realized...Research converged on a fundamental policy conclusion: to reduce health inequalities, the structural conditions that put people “at risk of risks” ...should be the focus of ameliorative programs and policies.”

By virtue of there being many sources of stress stemming from living in a cold home with ADRD, its very nature makes it a prime source of cumulative stress. It also generates many sub-optimal outcomes for wellbeing. A multiple pathways model in which escalating stress levels are harmful in themselves, but can additionally initiate supplementary circles of risk associated with understandable but maladaptive responses such as increased alcohol intake and loss of appetite, will almost certainly provide the best model linking the multi-dimensional concept we define as a cold
and damp home with the multi-dimensional concept we know as quality of life for people living with ADRD. As Thoits reminds us, very few of the solutions which can dislocate these causal pathways are ones which reside in people. They reside upstream.

It can take 3 years or longer between the first signs of changes in behaviour and the person being given a diagnosis of ADRD. Some of this delay may be caused by people’s reluctance to seek help, resistance to losing independence, fear of stigma and social isolation, and many other challenges associated with being given a diagnosis of this kind. However, during such a long period of increasing mental frailty, people may be living in homes which are increasingly risky in terms of thermal comfort levels. As noted earlier in this report, 50% of people who were living with ADRD at the time of death never had the condition diagnosed let alone treated. For these people, even less is known of how they managed to regulate their thermal comfort.

As a final synthesis, Figure 8 illustrates the variety of potential pathways by which excess winter deaths among people living with ADRD may come about. Of particular note is the extent to which many of the contributors derive from different aspects of impairment in people’s cognitive functioning, namely instrumental thinking (i.e. the link between cause and effect), mood, executive function (knowing how to carry out a task), perception, and social skills. Whilst public understanding of ADRD commonly packages these impairments collectively into “loss of memory”, they are in fact much more fine-grained impairments, some of which can be actively supported by carers in order to reduce risk. For example, if dressing inappropriately derives at least in part from not perceiving what is “appropriate” in a particular season, perhaps packing away summer clothes in winter might constrain people’s choice when they are dressing in the mornings. If executive functions around knowing how to prepare a meal are becoming impaired, then (as carers told us) leaving notes or setting up the early parts of a cooking sequence, can be helpful in the earlier stages of the illness. Similarly, mood is a particularly malleable aspect of psychological functioning, which can be lifted in a variety of ways, including lighting, activities (though not too far removed from routines), and drug treatments.

What is also apparent from Figure 8 is that each of these potential contributors seems almost unremarkable – and hitherto also unremarked. But taken together, they add up to what could be construed as a perfect storm of risk factors, especially because many of them tend to co-occur at the same time. Their humdrum nature belies their potential – when acting together – to create lethal living conditions for those who can no longer counteract them.
Recommendations

Carers’ recommendations

- CCTV monitoring (which would not infringe privacy rights)
- Overnight care assistance
- More social activities for men with dementia – many clubs are more attractive to women
- Luncheon clubs to encourage nutrition and social inclusion
- A system for utility companies to be aware of customers with dementia, and a way of ensuring that bills are paid
- A designated telephone number with utility providers, so that people with dementia are able to speak to a person and not a digital message that required option selection
- More dementia awareness training for retailers, cafés and other public buildings
- A risk-free means of boiling water to make a hot drink
- Warm memory foam lining for supportive chairs which are otherwise not ‘cosy’
- A voice-activated gadget for the front door to remind people to wear a coat
- A special locking device for PVC doors, which currently need to be locked with a key – if left unlocked, the house is open to anyone.

Recommendations for further research

- Analyses of EWD’s among people with ADRD, focusing on the place of residence at the time of death. If we understand more about the proportion of people living independently when they died compared to the proportion in residential or nursing care, this could guide us closer towards some of the most likely causes of this phenomenon; this data is available from 2005 onwards in the UK’s register of deaths
- Co-morbidities at the time of death – this may shed light on some of the physiological pathways by which risk of EWD is exacerbated among people with ADRD
- Temperature monitors installed in the homes of at least 500 people living at home with ADRD; these are now cheap to purchase, easy to install, and easy to monitor remotely through simple mobile phone technology.

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7 None of the carers expressed an awareness of Priority Service Registers, which are required by law among utility providers in the UK; all of those being cared for would have been eligible for registration.
Recommendations for utility providers

- For those who do receive a diagnosis of ADRD, an energy audit of people’s homes - at the earliest opportunity post-diagnosis - could ensure that homes are made more fit for purpose, with a view to future-proofing them to afford long-term protection.
- Energy-related measures are made available which are tailored specifically to the needs of people living with ADRD. These are unlikely to be confined to measures related to energy efficiency.
- At diagnosis, people with ADRD are offered the choice of being registered as a Priority Services customer with their electricity and heating providers.
- Energy companies obligated to deliver energy efficiency packages are encouraged to develop specialised services and packages for people with ADRD, in close consultation with the person and their carers. For example timers, temperature monitors, movement sensitive lighting systems could all be included in packages made available.
- During the current smart meter rollout in the UK, people with ADRD are classified as vulnerable customers, and are therefore unlikely to be offered one. Smart meter installations in the homes of people with ADRD should be encouraged, since these devices allow half-hourly monitoring of energy use, and can act as early warning systems related to unusual patterns of energy use (e.g. low consumption, sporadic consumption, excess consumption, consumption patterns out of kilter with the prevailing temperatures, etc.).

Recommendations for organisations supporting people with ADRD

- Efforts should be scaled up to ensure that organisations who support people with ADRD take the issue of excess winter deaths among their client group more seriously. We were especially concerned at the lack of response we experienced when attempting to engage these organisations in our research, despite sending them a full account of the scale of this problem.
- Wider and more informative dissemination programmes are supported, so that carers can be more aware of the dangers of thermal insensitivities among people living with ADRD, and the facilities that are available to protect them from both excess cold and heat.
Sources


DSDC (2012). http://dementia.stir.ac.uk


