In this informal pilot study, the cross-generational backgrounds of 60 people with late onset dementia were investigated and then compared with those of 60 people who retained all their mental faculties despite an elevated statistical risk of dementia in late life. Civil records dating back to 1837 were used to explore each person’s family history for clues about the early experience of the generations who immediately preceded them. The differences which emerged between the two groups were striking, with the backgrounds of the dementia sample containing significantly more incidences of premature loss than those of the comparison group. The findings are described and analysed with particular regard to Attachment Theory.

Introduction

 Relatives and front-line care staff often notice a history of trauma in the lives of people with dementia. Investigations into the backgrounds of an initial 51 people with dementia identified what appeared to be unusually high levels of childhood loss, particularly the death of fathers*. Thirty nine of these original 51 people had researchable British origins, and I was gradually able to bring my sample size from 39 up to 45 as new names became known to me.

An instance of particularly severe mothering in one of the early cases led me to research the mother’s background for clues as to its origins. This was enlightening, and it alerted me to the potential usefulness of investigating the backgrounds of the other 44 people too. A pattern started to emerge of what were, in my genealogical experience, uncommonly high levels of childhood bereavement in the early lives of my sample’s parents and grandparents. Most striking was the compound nature of the childhood bereavements suffered across two or more generations by many families in this study. An analysis of the results based on Attachment Theory suggested that few amongst this informal sample of 45 people with dementia had backgrounds conducive to receiving early security of attachment to a primary attachment figure. Secure early attachment has elsewhere been shown to be a prerequisite for emotional resilience in adult life, particularly in the face of trauma.

Despite this being an unfunded project, I then decided similar research was needed into the cross-generational backgrounds of a carefully selected comparison group, albeit again an informal one. By now, my dementia sample had swelled to 55. I made requests in my home community, to all likely e-mail contacts, and to Family History Society groups in the county where I live and its neighbour, for the names of 55 people, born in the C20th, who remained dementia free

• despite having lived to over 80yrs
• and despite having been widowed, divorced or never married
• and despite having lived alone at the end of their life
• and, if possible, despite having themself cared for a spouse with dementia

After an unpromising start, a sudden rush of responses provided 60 suitable names. Rather than distort the randomness of the comparison group by filtering any nominees out, I successfully appealed to my most recent informants for further names to bring the dementia sample up to a corresponding 60 in total.

The original people in my dementia sample had been taken from the UK Alzheimer’s website, or from biographical material in the public domain as well as from any private informants who could help me. The sample was therefore random but not randomised. No more than one person was included in the study from any genetic line, even when there had been more than one instance of dementia in the family.
The Composition of the Two Groups

Although premature loss tends to be dismissed as a common feature of life in Britain in the C19th and early C20th, it became very clear from my genealogical researches that some families were far worse affected than others by the ravages of industrialization and urbanization.

Factors such as

• long hours in harsh working environments
• low pay and inadequate nutrition
• overcrowded living conditions
• infectious disease
• unsafe urban water supplies
• minimal education

trapped many people in poverty and increased their risk of dying prematurely.

My findings led me to wonder if the inequalities of Victorian society might now be distorting our perception of the causes of dementia. Low socio-economic status and limited education, for instance, have been linked to a heightened risk of dementia but these are both characteristics associated with lack of opportunity in preceding generations.

The 120 people in this study came from various social backgrounds, but I was not in a position systematically to match them according to socio-economic status. I was, however, able to maximize the late life risk of dementia in the comparison group according to established research on age, marital status, lone living etc. As will be seen from Fig 1 below, the late life risk of dementia within the comparison group exceeded that in the dementia sample on all such criteria.

Fig. 1

<table>
<thead>
<tr>
<th>Composition of Dementia Group : Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age of Dementia Group = 82yrs 5mths</td>
</tr>
<tr>
<td>Comparison Group = 88yrs 2mths</td>
</tr>
</tbody>
</table>

- Female subjects
- Male subjects
- Spouse still living
- Widowed
- Years widowed
- Divorced
- Life-long single
- Cared for Spouse
- Graduates

Number of :- 0 5 10 15 20 25 30 35 40 45 50 55 60
Marital Status and Dementia Risk

Having a living spouse has consistently been found by research to confer significant protection against dementia. Nevertheless, 18 of the dementia sample (30%) had living spouses. None of the comparison group had this protection at the end of their lives.

Having, in later life, a spouse with dementia has been linked with a significant increase in the risk of dementia (e.g. 6-fold in one large community study). Two people in the dementia sample had experienced their partner having dementia, although one of them - the man - had had nothing at all to do with providing any care for his wife (when she had cancer in mid-life) or when she developed Alzheimer’s. Four people in the comparison group (2 men and 2 women) had had spouses with dementia and cared for them.

There were 31 widow/ers in the dementia sample and 54 in the comparison group, and they were widowed for an average 16yrs 7mths and 18yrs 2mths respectively. Two of the dementia sample had been widowed twice, as had one of the comparison group.

Widowers were markedly less common than widows in both groups, and were widowed for less time. The 6 widowers in the dementia sample had been widowed for an average of 12yrs 2mths, with two of them developing dementia within 3 years of their wives’ deaths. The 17 widowers in the comparison group were widowed for an average of 13yrs 6mths.

Only one person in the dementia sample was single, compared with 5 in the comparison group.

For divorcé/es the position was reversed, with there being only 1 divorcée in the comparison group but 5 in the dementia sample (4 women, 1 man). All 6 divorcé/es had spent the vast majority of their adult lives without a spouse.

Nine men out of only 17 men with dementia in my study (i.e. 53% of all men in the dementia sample) were married when their dementia manifested - as must surely have been the additional man who died of Alzheimer’s only a year after losing his wife. The number of married women with dementia was also 9, but they formed only 21% of the 43 women in the sample. Another way of looking at this is that men formed 50% of the married dementia subjects despite constituting only 22% of the whole dementia sample. These findings do not seem at variance with those of the large community study in Cache County – Fig 2 refers – and I think they raise some important new questions.

Fig. 2

<table>
<thead>
<tr>
<th>2,442 subjects (1,221 married couples) aged 65 and older from Northern Utah, USA, without dementia at onset, were studied for up to 12 years to monitor for onset of dementia in husbands, wives or both.</th>
</tr>
</thead>
<tbody>
<tr>
<td>During this time:-</td>
</tr>
<tr>
<td>125 cases of dementia only in the husband were diagnosed</td>
</tr>
<tr>
<td>70 only in the wife, and</td>
</tr>
<tr>
<td>30 where both spouses were diagnosed (60 people).</td>
</tr>
<tr>
<td>The researchers, led by Dr. Maria Norton of Utah State University, USA, adjusted for socioeconomic status, a significant predictor of many health-related outcomes including dementia, to control for shared environmental exposures that might influence risk for dementia in both spouses.</td>
</tr>
</tbody>
</table>
When compared to the men with dementia in my study, the women with dementia

- were older
- were much more likely to have suffered the loss of their marital partner
- were more likely be a widow, and widowed for longer
- were less likely to have Alzheimer’s Disease (AD)* as their particular form of dementia
- were particularly unlikely to have both Alzheimer’s Disease and a spouse

Fig. 3

<table>
<thead>
<tr>
<th>GENDER WITHIN THE DEMENTIA SAMPLE</th>
<th>TOTAL</th>
<th>MALES</th>
<th>FEMALES</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of people with dementia</td>
<td>60 (100%)</td>
<td>17 (28%)</td>
<td>43 (72%)</td>
</tr>
<tr>
<td>No. married</td>
<td>18 (30%)</td>
<td>9 (15%)</td>
<td>9 (15%)</td>
</tr>
<tr>
<td>No. with definite AD</td>
<td>15 (25%)</td>
<td>10 (17%)</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Married, &amp; with AD</td>
<td>9 (15%)</td>
<td>7 (12%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>No. widowed</td>
<td>32 (53%)</td>
<td>6 (10%)</td>
<td>26 (43%)</td>
</tr>
<tr>
<td>Percentage of all widow/ers</td>
<td>100%</td>
<td>19%</td>
<td>81%</td>
</tr>
<tr>
<td>Average time widowed</td>
<td>16yrs 8mths</td>
<td>12yrs 1mth</td>
<td>18yrs</td>
</tr>
<tr>
<td>Average age</td>
<td>82yrs 5mths</td>
<td>80yrs 11mths</td>
<td>83yrs 3mths</td>
</tr>
</tbody>
</table>

Age remains the single best predictor of dementia risk. The mean age of the dementia sample, either at death (the vast majority) or currently, was 82yrs 5mths – but this is an over-estimate relative to that of the comparison group, as dementia has been shown to affect people for an average of 5-7yrs before they die. The mean age of the comparison group was calculated from the ages at which 56 of the group had died, together with the current ages of the 4 living people in the group, all of who were lively-minded nonagenarians managing in the community despite, in some instances, now having awkward combinations of sensory and physical disabilities. One person, for instance, with no relatives or neighbours to assist her, continued to manage solitary living despite being registered blind for several years and now losing her hearing. The mean age in the comparison group came out at 88yrs 2mths (range 80yrs - 102yrs).

Education is seen as protective against dementia, but the dementia sample contained 4 graduates, 3 of whom were women (i.e. exceptionally high achievers for their era). There were only 2 graduates in the comparison group, 1 female and 1 male.

*There have always been, and remain, complications affecting the definitive diagnosis of Alzheimer’s Disease (A.D), even post mortem. The low rate of confirmed A.D. to other dementias in my sample was likely to be a function of significant underdiagnosis, but there is no reason why underdiagnosis should have applied unequally across the sexes.
Family Size
Victoria Moceri, at the University of Washington in 2000, carried out a study of 770 people aged 60 and older who were members of a large health maintenance organization in Seattle. Of the participants, 393 had Alzheimer's disease (AD) and 377 had no signs of dementia. Every additional child in any family was found to increase the Alzheimer’s risk of the sibling set by 8%. This increase in risk was attributed to large families being more likely to come from the lower socioeconomic levels, and therefore to be more likely to have children with poor (brain) growth rates. I found no similar link with larger families, even amongst the confirmed instances of AD rather than other forms of dementia (Fig. 4 refers).

Fig. 4

Higher paternal age at conception has been found to increase the risk of gene mutations which compromise the offspring’s brain. The fathers of the people in the comparison group were at least as old as those of the dementia sample. The differences between the two groups cannot therefore be attributed to any higher paternal age at conception within the dementia sample.

Fig. 5

<table>
<thead>
<tr>
<th>Average age of fathers in Dementia Group</th>
<th>31yr 1mth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control Group</td>
<td>32yr 3mth</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over 50 years</td>
<td></td>
</tr>
<tr>
<td>45 - 49 years</td>
<td></td>
</tr>
<tr>
<td>40 - 44 years</td>
<td></td>
</tr>
<tr>
<td>35 - 39 years</td>
<td></td>
</tr>
<tr>
<td>30 - 34 years</td>
<td></td>
</tr>
<tr>
<td>25 - 29 years</td>
<td></td>
</tr>
<tr>
<td>20 - 24 years</td>
<td></td>
</tr>
<tr>
<td>Under 19 years</td>
<td></td>
</tr>
</tbody>
</table>
Loss of Parents in People’s Own Childhoods

Fig. 6

LOSS OF PRIMARY ATTACHMENT FIGURE (PAF) DURING CHILDHOOD

COMPARISON GROUP PEOPLE (CGP)  
N = 60

Age at time of mother’s death
0 (raised by maternal aunt & uncle. Birth father died when 11)
7.5yrs
8yrs
9yrs

PEOPLE WITH DEMENTIA (PWD)  
N=60

Age at time of mother’s death
2.75yrs (T.B. - mother progressively ill beforehand)
3yrs
7yrs (T.B. – which then killed father when child 13yrs)
8yrs
13yrs
14yrs (then chronically ill father died within 6mths.)

EARLY CHILDHOOD SEPARATIONS FROM PAFs

The 9yr old above had also been in care of severe aunt, aged 2yrs, after next sib born  
4 CGPs experienced institutional care (3 after the age of 6yrs.)
1 PWD was evacuated during WWII, aged 10yrs
4 PWD were hospital inpatients for up to several months
1 PWD went abroad to boarding school & relatives aged 8yrs
1 PWD went to severe grandmother, aged 14yrs, when next (frail) sibling was born

Jane Sherwood, June 2013

Fig. 7

LOSS OF FATHERS DURING CHILDHOOD

COMPARISON GROUP PEOPLE  N = 60

Age at time of father’s death
1yr
11yrs (after mother died at birth. Raised by maternal aunt & uncle).
12.75yrs
14yrs

PEOPLE WITH DEMENTIA  N = 60

Age at time of father’s death
1yr
2yrs
3yrs
6yrs
7yrs (WW1 casualty)
8yrs
9yrs
13yrs (T.B. - child’s mother already dead)
15yrs (chronically ill & recently widowed)
16yrs (progressive, debilitating illness)
18yrs
19yrs (chronically ill)

LONG TERM PATERNAL ABSENCES

1 other father served in WW1 whilst CGP was under 5yrs
2 other fathers served in WW1 or WW2 while PWD were under 5yrs
5 other fathers served in WW1 or WW2 while PWD were under 5yrs
2 other fathers served in WW1 or WW2 from when PWD were 6-8yrs old
2 other fathers deserted their families (one when PWD was 4, the other when PWD was 11)

Jane Sherwood, June 2013
Comparative Results

A striking difference emerged between the two groups in that the dementia sample had suffered significantly more premature bereavement across recent generations than had the comparison group.

Western society has become blasé about the personal impact of high infant (and adult) mortality in the C19th and early C20th. There is no good reason to presume that a Victorian woman who lost a child felt any less distress than a grief-stricken woman feels today. She may well have had less opportunity to grieve, however. In the 120 backgrounds in this study, I came across women who lost as many as 11 children. One unrecognized implication of infant mortality on such a scale is that some surviving children would have experienced their primary attachment figure as recently-bereaved through much of their early life. Some of the Seattle results on family size referred to on the previous page surprised the researchers, and a different way of looking at large families is that the statistical risk of a young mother encountering loss of a child increases with each new infant born to her.

It was suggested that I try using my social work knowledge and experience of the impact of broken attachments to apply a simple 10-point scale to the number and severity of the childhood losses in the maternal line of each of the 120 backgrounds in my study. It was not possible to carry out this exercise blind, nor did I have a collaborator who could cross-check the scores I allocated, so I erred on the side of generosity when scoring any rather limited information about the backgrounds of people in the comparison group (e.g. I would assume a lost child in those instances when there was a gap in sibling births but no viable way of confirming a correct birth & death). A team approach will be needed to establish a reliable scale for future use. This was just an initial effort to convey, in visual form, the striking differences I had been noticing amongst the family trees I had drawn up. I was guided by the following parameters:-

- Backgrounds where there had been no bereavements during the early life of the individual in my study, or of their mother, or of their maternal grandmother, scored 0.
- Backgrounds scored 9 where the catalogue of childhood losses/separations was so extreme that it was hard to imagine how any further tragedies could have made early life significantly worse.
- All the remaining backgrounds were ranked in relation to these two extreme scores and to each other.

![Fig. 8](image-url)
Figure 8 shows the over-all results of this trial exercise in quantifying transgenerational attachment issues. It will be noted that:

- 80% of the comparison group scored 3 or less (below the blue line), whereas 91% of the dementia group scored 4 or more (above the blue line)
- Twelve people (20%) in the comparison group had no identifiable instances of early loss in their backgrounds so scored 0, as against only one person in the dementia sample.
- There were only 2 backgrounds which scored the maximum 9, both from the 60-strong dementia sample rather than the comparison group.

Figure 9 (below), entitled ‘ALMA’, is a selective family tree illustrating a combined personal and maternal early background which I scored at 9 on a 0 - 9 scale of attachment traumas. The fact that the subject encountered widowhood in her 60s was not taken into account when scoring, as this was a late-life event. (For the sake of completeness I later investigated 2 earlier generations than are shown here.)

**Fig. 9 – ‘ALMA’** (Identifying details have been changed).

One of the 2 instances of a person with dementia whose own/ maternal background was scored at 9
Resilience in the Comparison Group

The highest-scoring people in the comparison group, i.e. those whose backgrounds were allocated a score of 6, all achieved this on account of having some childhood experience of institutional care.

It might be relevant, though, that three of them were at least 6 years old by the time of their residential admission so they may have experienced some secure attachment within their families until that point.

One of these 3 children also had the good fortune to be cared for in a Family Group Home by a kindly housemother (i.e. primary attachment figure) with whom he kept in touch in adulthood.

The fourth person, the one whose time of admission is not known, suffered an impersonal and probably punitive workhouse upbringing consequent upon her bigamous father’s failure to support his 2nd wife and family.

The resilience of the high-scorers in the comparison group is interesting and it may in time prove significant that they all had siblings who suffered the same fate as they did.

When I was considering with the son of one of them the concept that the burying of traumatic memory might constitute a route into dementia, he commented that his father and numerous uncles and aunts had the advantage of being able to complain heartily to each other about their childhood experience whenever they met at family gatherings over the years because their father was profoundly deaf and couldn’t hear what they were saying(!)

Having someone to believe and validate ones traumatic experience is an essential part of the healing process.

Siblings may, at least sometimes, be able to help each other keep painful memories within conscious awareness rather than feel obliged to bury them.

The number of singletons viz-a-viz eldest siblings, youngest siblings etc. did not appear significantly different in the dementia sample than in the comparison group.

These high scores in the comparison group could, of course, be a function of over-generous scoring of instances of separation (rather than permanent loss) on my part. My generous scoring of separations, though, was influenced by my knowledge that, out of my original 51 people with dementia:

- 8 had experienced separations in childhood, often reportedly highly traumatic, which were occasioned by being sent to boarding school – sometimes in another country - and/or to live away from the relatives with whom they started life

- 4 others (all of whom had British backgrounds so went on to figure in my dementia sample) had coped, unaccompanied by a familiar adult, with childhood in-patient hospital stays and distressing treatments in an era of very limited parental visiting.

- 6 others had been raised by unsupported mothers following parental disharmony and eventual marital breakdown
Comparative information about the timing of key bereavements in the lives of mothers of the 120 people in my study is shown at Fig. 10 below. Paternal backgrounds were equally tragic but I had noticed very early on, from the backgrounds of my original 51 names of people with dementia, that the common factor in the vast majority of their histories was an early lack of uninterrupted ‘mothering’. By this, I mean that the events in their childhoods were such that they were unlikely to have experienced uninterrupted early care from their primary attachment figure (PAF).

Information about maternal grandmothers’ childhoods is harder to obtain. Deaths in England and Wales are currently indexed only by name until the 1870s, with no reference to the deceased person’s age. Without purchasing enormous numbers of speculative death certificates at £9.25 each, lost siblings of maternal grandmothers (MGMs) born in the C19th are particularly difficult to identify accurately. Maternal grandmothers in the 2 groups could nevertheless be traced as having lost a similar number of mothers as each other in childhood, viz:

- 5 MGMs in the comparison group lost their mothers, at birth, 3yrs, 3.75yrs, 12-13rs, & 13-14yrs respectively.
- 7 MGMs in the dementia group lost their mothers, at ages 3yrs, 8yrs, 9-12yrs, 10yrs, 13yrs, 17yrs, & 17yrs respectively.

(I have included the 17yr olds because teenage loss of mother has been linked with a heightened risk of AD – Cache County Study)

There was a striking difference, though, between the fathering/supported母亲ing experienced in childhood by the two groups of maternal grandmothers. Significantly more MGMs in the dementia sample were illegitimate or had fathers die than in the comparison group. Fig. 10 refers.
The Bereaved Primary Attachment Figure

A child’s primary attachment figure (PAF) is most commonly, but not necessarily, the biological mother. For the sake of clarity, I shall refer to the PAF as female/mother.

The task facing a recently bereaved mother is an unenviable one. There is no ideal way for her to shield her young children from the potential fall-out of the tragedy which has befallen her. If she has a history of unresolved childhood loss, this is likely to complicate her ability to mourn effectively. “Loss : Sadness and Depression”, the final part of John Bowlby’s trilogy on Attachment and Loss, remains one of the most useful texts for helping us understand the devastating impact of the death of a loved one.

• If the mother tries to behave as if nothing has happened, her children are likely to sense that this is not so – especially in the years before they become skilled at using and understanding language. Sudden, inexplicable, changes in parental behaviour confuse and easily frighten children. The younger the child, the fewer defensive strategies he will have at his disposal. Painful feelings which go unrecognized and remain unresolved in the absence of sensitive adult intervention all too easily get buried. Defensive patterns quickly become set - and handed down within the family.

• A mother who has lost her husband is particularly ill-placed. If she tries to be reasonably open with her feelings, or ever breaks down in front of her young child(ren), they are likely to fear losing their surviving parent and being abandoned. Children’s typical fears in situations such as these were not recognized and understood until the mid-C20th. A father’s death (or wartime front line service) also deprives his wife of key emotional support just when she and, through her, their young children are likely to need it most.

• If it is a child who has died, the surviving siblings can readily mistake their mother’s grief as indicating that she loved her lost child more, and that their own feelings are relatively unimportant to her. This is another route to children learning to dismiss their own feelings.

• If a mother is open about what has happened but covers up her distress about it, this is what her young children will learn, by example and the firing of mirror neurons, to do in similarly painful emotional circumstances. They will thereby potentially store up a catalogue of unprocessed traumatic experiences throughout life.

• The inclination to cry is particularly problematic for mothers and young children alike. Any mother who is trying to stifle a need to weep will find it very difficult to respond with anything like her usual sensitivity and generosity of spirit to the need for constant closeness, reassurance and encouragement; the clinging, tears and tantrums etc. which characterize normal toddlerhood. Children, for their part, are keen to please their caregivers, and the natural and healthy inclination to cry can easily be lost. Several of my informants separately commented that their relative/friend with dementia was never able to cry.

• Without sensitive and sympathetic early handling of their emotions, children are in danger of learning that their feelings are of no value, and to grow up disconnected from them. Learning not to feel anger, for instance, invites exploitation and can easily produce depression. Shared roots in early childhood adversity could help account for the connection between depression and dementia, although the biological model has so far presumed straightforward cause-and-effect between depression and dementia. Lifelong disconnection from one’s feelings might also explain why Alzheimer’s Disease can seem to re-introduce people to ‘lost’ parts of their personality e.g. with people who were mild or submissive becoming demanding or aggressive, or those who always seemed ‘tough’ being reduced to unexpected anxiety or tears etc..

These are just some of the ways in which death within the close family can impact on young children’s emotional development, and on the ways in which they will habitually handle difficult feelings in
Resilience and Optimism

There has been considerable recent investigation into resilience, especially amongst the bereaved*. Most adults can be shown to make a satisfactory recovery from bereavement without outside intervention (although good social support is beneficial). Optimism, likewise, has been receiving a great deal of academic attention, and has been shown to benefit the neuronal connections within the brain. Neither the work on resilience nor the work on optimism, however, disproves that there may be unseen, very long-term consequences of finding ways of avoiding fully registering and processing grief. Compulsive self reliance, developed as a coping strategy in childhood but leaving the adult emotionally vulnerable, can all too easily be mistaken for true resilience.

When someone shuts out troubling feelings without even noticing them occurring, their distressing experiences remain unprocessed. Keeping busy can be a useful distraction against feeling and introspection (which may contribute to its usefulness as an apparent protection against dementia). But traumatic memories may become harder to keep buried as the years pass.

There were certainly people in my dementia sample who were exceptionally good at keeping up their spirits throughout life, even when faced with bereavement. But the experience of sadness has its place in allowing us to move on in a healthy way after tragedy strikes. A healthy way is one that does not expose us to the risk of later converting unprocessed traumatic experience into physical or psychological expressions of dis-ease. The current pervasiveness of dementia may itself be suggesting we need to review how we can best integrate the experience of interpersonal loss and other traumas.

The Relevance of a Secure Base

Some of the biological changes associated with dementia are also associated with insecure attachment or trauma. Altered immunity, altered cortisol responsiveness, altered gene expression, altered glucose regulation, and altered neuropeptide functioning are just a few examples of this. The concepts of allostatic load and cognitive reserve are central to current thinking about dementia, and they too may conceivably be affected by attachment traumas which are particularly ill-timed. The lack of a secure base and the inability to regulate ones emotions can result in painful feelings being habitually but unconsciously kept out of awareness, which is known to be injurious to long-term physical as well as mental health.

The lack of a secure base is not generally identifiable without detailed and highly skilled assessment, but factors such as marital breakdown and mental illness are likely indicators. Post Traumatic Stress Disorder (PTSD), like clinical depression/Major Depressive Disorder (MDD), has been linked with a heightened risk of dementia and also with adverse childhood experience.

Around 40% of the population are thought to lack a secure base but, in common with the population at large, not all 40% will survive long enough to be at serious risk of dementia.

The commonly occurring behaviours known as parent fixation and parent orientation are taken to represent efforts by people with dementia to re-capture the security enjoyed in early childhood, but my findings lead me to suspect they may actually represent renewed, desperate attempts to elicit a security of attachment that never was. It is interesting that the principles of attachment theory are increasingly being applied in dementia care settings, with encouraging results. Why should these principles make a significant difference to problems that are not somehow attachment based?

We need to be very careful, though, to check the context of expressed desires such as to “go home because my mother’s expecting me”. I asked the daughter of a nursing home resident who had started expressing such a desire, if her mother had perhaps cared for her grandmother in later life? The answer was immediately that she had done, for very many years. Maybe what this resident, and some others, was expressing here was an anxiety about the wellbeing of an aged parent who used to depend on her. (Children whose early attachment needs were poorly met can also grow up feeling overly responsible for the care of others.)
Late Life Stress

Late life tends to bring particular challenges to attachment security. The longer someone lives, the more bereavements s/he is likely to encounter. Not only does each bereavement constitute a personal loss but it also depletes the number of potential attachment figures who might offer support in adversity – a potential ‘safe haven’. Some of the particular late-life challenges which came to my attention in the context of my dementia enquiries were:-

• Recent widowhood
• Imminent loss of one’s partner
• Intrusive memories of trauma, without access to sufficiently effective distraction
• Sudden indications that a spouse is vulnerable, or a reminder that s/he is mortal
• The particularly traumatic loss of a loved one e.g. by suicide, or accident, or in another country
• Loss of one’s child or grandchild
• An unfortunate cluster of losses of close family members
• For those living alone, the imminent loss of a last surviving sibling/friend/neighbour
• A hospital in-patient episode, especially if such an instance had also occurred in early life
• The failure of one’s partner to provide reciprocal care when needed, or retirement looming with an unsympathetic or hostile partner

Not everyone with an insecure base who survives into late old age will have the misfortune to encounter traumatic experiences such as these. But I have come to think that people who have grown up without adult help to tolerate and process painful feelings (i.e. effective emotion regulation) can find the extreme sadness or fear generated by late life events such as these overwhelming or unbearable. Accumulated tragedy and early loss across recent generations may well conspire to deprive children of adequate positive experience of early attachment to see them safely through a long life which happens to have a significant emotional challenge at its end.

The Scope to Intervene

Trauma is already being overcome in other fields, and without the overwhelming horror of it needing to be re-experienced. So too are the remnants of actual or threatened personal loss, such as emotional overwhelm, disordered mourning, or fear for ones survival – which I am suggesting collectively may be the triggers for dementia.

It is likely always to be impossible to prove that someone would have had dementia were it not for a given intervention. Nevertheless, if my findings are replicated, a sensible approach might be for anyone who finds their memory letting them down to consider seeking skilled therapeutic help to explore what fears, memories or uncomfortable feelings their subconscious mind may be struggling – by increasingly desperate means - to keep out of their conscious awareness.

Mind, body and spirit still tend to be dealt with in western society as separate entities. Remarkably little time and interest is given to the part played by psychological factors in the creation of illness. The experience of dementia is recognized as seriously undermining to people’s confidence in their own abilities and their sense of security. My social work perception, though, based on published case studies and research findings as well as on my own experience, is that dementia often seems to follow in the wake of destabilizing changes in circumstance, if not more overt trauma.
Implications for Future Research and for Social Policy

From a cross-cultural perspective, might the changes brought about by industrialization & urbanization have increased the incidence of disordered mourning/ burying of painful feelings - thereby helping to fuel current high dementia rates in the developed world? Lower rates of dementia in less developed countries are often put down to lack of awareness/ diagnosis/reporting. Is it chance, though, that India has particularly low levels of Alzheimer’s Disease, even allowing for the low incidence there of the ApoE4 gene? Or might the majority Indian religion, Hinduism, be providing just the kind of framework which people need in order to recover from personal bereavement i.e. an expectation that the grief-stricken should be encouraged to express their emotions, and be given practical support while they attend to doing so? Other indigenous peoples likewise have retained beliefs and practices which respect and restore emotional and spiritual wellbeing after loss and other traumas.

From an epidemiological perspective, was it just chance/cohort effect that I came across a high proportion of people with dementia who were very young children during one or other of the world wars, with absent fathers whose wives had tragic early backgrounds which were likely to render them uncommonly vulnerable emotionally? Future research needs to allow for the possibility that being a young child in wartime circumstances such as these might hold some relevance to late life dementia risk.

When I reviewed the birth timings of my 2 groups against the timing of the 2 world wars (1914-1918 and 1939-1945), the only striking difference was in the period 1900-1910, when just 3 of the 60 people with dementia were born as against 22 people in the comparison group. The case examples I have come across suggest we may need to be alert to the particularly unfortunate timing for young children of emotionally vulnerable mothers in WW1, who then went on to experience an especially traumatic WW2 as adults. Likewise, young children whose fathers came back particularly damaged emotionally by their WW1 military experience, and those young children who were separated from both their parents during the evacuation of British cities in WW2 may, under my analysis, be especially vulnerable to dementia. In some countries, including the U.K., the dementia rate is now falling. Childhoods spent relatively safely between the two world wars could be relevant to this, reinforcing the need to pay special attention to the precise choice of birth cohort in future research.

Contrary to government expectation, if my analysis is correct the ‘Baby Boom’ generation of people who were born in Britain in the wake of WW2 may well be less vulnerable to dementia than their immediate predecessors, because:-

• Post-war children by definition had fathers who survived the conflict
• The nutrition & therefore the physical resilience of all children benefited from the post-WW2 introduction of free daily pasteurised milk, and of subsidised meals in all state schools
• Child deaths/sibling losses fell as children started to be vaccinated against highly infectious diseases such as polio, diphtheria and scarlet fever
• The National Health Service began in 1948, making free treatment available to all, including new antibiotics
• The rate at which young adults/parents were dying fell drastically after WW2 in response to additional factors such as mass screening for T.B. coupled with the discovery of streptomycin
Recent findings such as that cancer and Alzheimer’s, and arthritis and Alzheimer’s, rarely occur together are taken to indicate that cancer and arthritis must somehow ‘protect’ against Alzheimer’s. Another way of looking at cancer, or arthritis, or Alzheimer’s – or, for that matter, heart attacks, or strokes, or autoimmune diseases, or organ failure, etc. etc. - is that each represents a response to a different type of stress. Why should we expect any more than one of them occur in an organism trying to restore homeostasis in the face of a particular and distinct form of external or internal threat? (We also might do well to question why poor cardiovascular health has been linked with an increased risk of Alzheimer’s yet somehow fails to provide welcome and swift relief for the tortured Alzheimer’s sufferer via a fatal heart attack or stroke.)

In my study, 4 of the people with dementia had already survived cancer in mid/late life. Interestingly, 3 of them not only had AD despite already having had cancer, but they were amongst only 9 people with AD in my study who still had a living spouse.

**Gender and Marital Status**

The findings of my pilot study, coupled with those of the community-based Cache County Study, suggest there are some new questions we need to start asking about dementia in the context of gender and marital status. Page 3, and Figs 2 & 3 refer:-

1. Despite the known higher prevalence of dementia amongst elderly women than amongst elderly men, out of 1221 retired married couples followed up over a 12yr period in Cache County, **125 husbands developed dementia but only 70 wives.** (There were also 30 couples where both spouses developed dementia, but it is unclear to me in which order.)

2. Men who had a spouse with dementia were found by the Cache County study to have an 11.9% increased risk of dementia themselves, against an increased risk of only 3.7% for women who had a spouse with dementia.

3. **Definite AD cases** represented only 25% (N=15) of my dementia sample but 50% (N=9) of those where there was a living spouse.

4. There is no good reason to suppose AD is diagnosed more frequently in one sex than the other. I found, though, that my dementia sample contained twice a many men (N=10) with AD as women (N=5) although men represented only 28% of my overall dementia sample.

5. Men with dementia in my study were be **almost 10 times** as likely as women with dementia to have AD despite being married. Elsewhere, however, research has found that men looking after wives with dementia tend to be coping with a greater burden of practical care than women who are looking after husbands with dementia.

**Marriage has consistently been found by researchers to protect against dementia.** Why, then – assuming my findings can be replicated across a much larger sample - might the supposed advantage of having an (able) living spouse increase the risk of Alzheimer’s viz-a-viz the other forms of dementia? Why, moreover, should the risk of AD be even higher if the living (able) spouse is female? And why should having had a female spouse dis-abled by dementia so significantly increase the risk of dementia in her widower?

*The Epidemiology and Prevention of Dementia (EUROdEm) study*

** Men accounted for 7 of the 9 people who had AD whilst married, whilst representing only 28% (N=17) of the overall dementia sample. Women accounted for only 2 of the 9 married people with AD whilst representing 72% of the overall dementia sample.
There was only 1 (female) divorcée in the comparison group but 5 divorcés in the dementia sample (4 women, 1 man). All 6 divorcé/es had spent the vast majority of their adult lives without a spouse. Two of the dementia sample had been completely abandoned by their husbands when their children were very young, and two others had themselves been wives who had abandoned their partners and dependent children without notice. The man with dementia whom I have counted as a divorcé left his wife for another woman, with whom he had a child before their relationship also quickly foundered. Two of the widows in the dementia sample had also been divorced earlier in their lives – one of them being a further example of a young mother abandoned by her husband. One of the married men with dementia had likewise had a previous marriage which ended in divorce (in the wake of a child’s death).

Thus 9 of the 59 people in the dementia sample who had ever married had experienced divorce/marital breakdown compared with no-one amongst the 55 (of 60) people in the comparison group who had chosen to marry. (And marital breakdown, as I have already mentioned, is a likely indicator of insecure attachment.)

**Widowhood**

Current prescriptions for retaining good cognitive function in late life show painfully little regard to the disadvantage most elderly women will have experienced throughout their adult lives.

The majority of current nursing home residents, for instance, are from generations where most women lacked the opportunity of an intellectually challenging and fulfilling career, and most lacked the money, time and energy for stimulating activities outside the home. Caring for others was generally their lot, in an era with less labour-saving devices than now, far fewer freezers, no supermarket ready-meals etc.

Women born before the war were expected by society to keep house for their menfolk and children, and to help frail elderly relatives remain in the community. Some wives whose husbands’ incomes were sufficient to support the family joined other women who had retired in providing unpaid voluntary services needed by vulnerable members of the community (e.g. by organizing and delivering ‘meals on wheels’ for the housebound). Many women, as now, provided daycare for young grandchildren through into their own retirement so that their adult children could work.

Competing domestic responsibilities condemned those from poorer households to low paid and menial jobs, which often involved working unsociable hours and could be physically exhausting. The worst-off could neither afford to leave, nor afford to retire fully when they reached state pension age.

The usefulness of all these essential but undervalued, demanding, and traditionally female activities in keeping people alert and engaged tends to be overlooked by research. Ironically, it took the Second World War to give many of these now elderly women, from whatever background, at least a glimpse of their true occupational capabilities.

There is now a plethora of official advice about the sorts of activities which older people should pursue in order to stave off dementia, but it can seem to bear little relation to the harsh realities of the lives of the oldest old, and particularly women. I also became very aware as a social worker across the age ranges that the activities outside the home which men and women in their 60s and 70s might enjoy and find stimulating were often beyond the energies of those of 80+ years.

* See for instance “Hard Work :Life in Low Pay Britain” by Polly Toynbee - published in 2003 but still applicable today

**This point is well illustrated in “The Girl from Station X” by Elisa Segrave, in which she describes her privileged mother’s struggle to keep house for her young husband, who went off to fight in the Second World War and the response she had to make to her young children’s needs. (This is a likely indicator of insecure attachment.)
Many elderly widows, even in the face of increasing physical infirmity, nevertheless remain active in mind and body by continuing to carry out the myriad tasks involved in independent living. They clean their homes (generally to a standard envied by their juniors); plan and manage their often frugal incomes; shop frequently for groceries, in amounts they can both afford and carry; plan, prepare and cook proper meals; do their own laundry and maybe some ironing; keep in touch with relatives and friends; tend their gardens if they have them; care for, exercise and clean up after any pets; help neighbours frailer than themselves; and also join in whatever social or voluntary activities are accessible to them at their current level of physical ability. Far from being the ‘couch potatoes’ of whom sports scientists and public health gurus despair, most elderly women well earn any time they get to sit down and relax.

This widespread pattern of everyday living amongst elderly widows is patently healthy enough for the vast majority. It can, however, all too easily be disrupted by unresolved mourning, chronic anxiety, depression, and/or incipient dementia - factors which together can conspire to cloud the picture of what really does, and does not, keep dementia at bay.

Health advisors and social planners also tend to assume everyone has personal access to a car with which to get to stimulating pursuits. Away from civic hubs of commercial & academic activity, one only has to pay attention to who is patiently waiting at bus stops or struggling along on foot in all weathers, to recognize the reality that many unsupported women, especially those old enough to have been born before WW2, have been getting up and out for exercise (with its likely attendant social engagement) every time they want to go anywhere at all.

Perhaps we should adjust our focus and start asking why it might be that so many solitary, and often care-worn, elderly women are needing to be looked after by someone else for a while before they die.

Conclusions

Dementia, like mental illness*, is far more common in subordinate groups in society (e.g. women, people of low socioeconomic status, racial minorities) than in dominant ones. It has also been common in British society for longer than we collectively choose to remember. I am old enough to recall traditional Victorian psychiatric, ‘subnormality’, and geriatric hospitals, whose large, impersonal and sometimes locked, back wards were populated by high numbers of distraught/confused and institutionalized elderly people, most of them women. Wretched lapses into unreality are not as new a phenomenon within British society as we like to believe, although they have rightly become less invisible and therefore harder to ignore.

Women form not only the vast majority of people with dementia (because of their increased susceptibility in oldest old age, as well as because they live longer than men) but they also form the vast majority of unpaid informal carers; the vast majority of very low-paid care employees; and now the vast majority of the high-fee paying care home users.

Meanwhile, institutions administering to people with dementia tend to be male-dominated, including government and the financial sector which, in the U.K., respectively allow and benefit from a lucrative system of for-profit care home provision. The purchase of dementia care at exorbitant and escalating prices is being left to ordinary people and, when they have no private means or when their personal resources run out, cash-strapped local authorities. Dementia is nevertheless presented by government and the media as an enormous current expense to the state/tax payer. This is disingenuous.

Where is this alleged state expense being incurred?

*See for instance “The Social Creation of Mental Illness” by Raymond Cochrane or “Creating Mental Illness” by Allan V. Horwitz
Funding for dementia research has been lamentably low in the UK relative to that for conditions which present earlier in life and, by contrast, affect at least as many men as women – such as cancer and heart disease.

As for NHS expenditure on dementia care, anyone who has encountered mixed-age NHS wards is likely to have witnessed the widespread failure of our general hospitals to make any adapted provision whatsoever for physically or mentally incapacitated elderly in-patients. Unacceptably low staffing levels in NHS hospitals mean that frail elderly patients tend to be left un-fed and sometimes un-toiled as well as completely un-stimulated. Even affording inpatient TV/‘phone, or visitors’ car parking at most U.K. hospitals has, through privatisation, become the preserve of those with above average means, thus increasing the isolation (and, ironically, thereby impeding the recovery) of the frailest elderly in-patients. This is especially the case in rural areas, where incomes are low and there is little if any public transport.

Defensive institutional processes, reinforced by a societal terror of ageing and a pathological obsession with youth, militate against proper investigation into social factors which may have been contributing to high dementia rates in unequal societies such as ours.

Research effort continues to focus on the cascade of intricate biological changes associated with (but not necessarily causing) dementia, or on identifying individual shortcomings which can be blamed for dementia’s occurrence. This latter approach demonises the underprivileged whilst allowing the best-resourced in society to feel relatively safe from dementia e.g. in the knowledge that they had a reasonably good material start in life; had a better than average education; have been equipped to enjoy reading and other intellectual pursuits; have not suffered the impact of a lifetime’s physical hardships; have not been mentally de-railed by unremitting powerlessness; and can afford to eat well, travel comfortably and benefit from an interesting and stimulating lifestyle etc..

Dementia particularly baffles us when supposed protective factors such as these mysteriously fail to protect. (Perhaps the prevailing paradigm is wrong.)

My findings, although they need confirming across much larger, formally controlled samples, suggest that there may be some particularly unfortunate combinations of early and late life experience which can cause people increasingly to withdraw from reality in a desperate bid to survive. The means by which a gradual mental shutdown is achieved is presumably a matter of individual biology.

From my perspective, the origins of dementia, and ways of intercepting it, may be proving elusive because we have yet to contemplate the possibility that psychology could hold the key that will unlock the complex biological puzzle.