

# INSIGHTS

A SERIES OF EVIDENCE SUMMARIES

59

# Dementia: attachment matters

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## Key points

- Attachment theory, most developed and applied to the early years, has relevance to our understanding of dementia and its impact on people and their family carers. Understanding attachment helps us to understand behaviours and responses to dementia.
- Attachment, an emotional link between two people which lasts through space and time, affects people's ability and willingness to relate to the world around them and can be a preventative factor in managing the symptoms and effects of dementia.
- Attachment can enhance the safety and security experienced by people living with dementia, can support them to maintain relationships, connect with their community and engage in support and care.

## Introduction

Dementia is an umbrella term for symptoms caused by over 100 brain conditions with Alzheimer's Disease being the most common. This complex range of conditions commonly referred to as dementia has been a global health priority since 2012 and described as 'an increasing threat to global health'. Indeed, the authors considered their report to be 'a resource that will facilitate governments, policy makers and other stakeholders to address the impact of dementia' (WHO, 2012, p7). Over 90,000 people in Scotland live with dementia and this is expected to rise in coming years at a rate of 20,000 per year (Scottish Government, 2017).

## Prioritising dementia in Scotland

Before dementia was established as a global health priority Scotland became one of the first countries to acknowledge the need for action on dementia when the first Scottish Dementia Strategy was launched (Scottish Government, 2010). It focussed on improvement to existing care pathways, strengthening integrated approaches and improving diagnosis levels. The strategy was

arguably the first in the world to reflect a rights-based approach, drawing as it did on the Charter of Rights for People with Dementia and their Carers in Scotland (Scottish Government, 2009).

A second national strategy (Scottish Government, 2013) introduced a guarantee of one year of support from a named practitioner for everyone in Scotland receiving a diagnosis of dementia. This was the first such guarantee in the world and was heavily informed by this rights-based approach. The second strategy also introduced a series of commitments that recognised people's rights to maintain community connections and social support, to be recognised as active citizens and to live in dementia friendly communities where they would feel included and at the heart of community life.

Now at the end of Scotland's third dementia strategy, (Scottish Government, 2017) the national commitments continue to make reference to the need to be person-centred in all approaches to support and care. Overall, the three national strategies to date, while not referencing attachment specifically, recognise the importance of connectedness and personal history in planning support and care.

During this time, national policy into practice initiatives have been led by academic institutions and third sector organisations including the University of Stirling's Dementia Services Development Centre, University of the West of Scotland's Centre for Policy and Practice in partnership with Alzheimer Scotland, Alzheimer Scotland itself and the Life Changes Trust.

## **Attachment: what is it and why is it important?**

Attachment has been described as 'an affectionate bond between two individuals that endures through space and time and serves to join them emotionally' (Fahlberg 1994, p14) and is a relational process linked to basic human survival.

While the understanding of attachment has developed since the early work of Bowlby (1969) and Ainsworth and colleagues (1978) who described patterns or styles of attachment beyond the straightforward secure and insecure, what has remained constant is an understanding that the building of secure attachments impacts on the ability of a child to understand the world they inhabit and to navigate their way through it successfully. The theory would suggest that children

whose needs are met in a timely, sensitive and loving way develop a sense of trust and a confidence in themselves. These early attachments help them to form close relationships, growing up knowing that when they need something, someone will help them. Much of the literature that focuses on the impact of attachment issues in adulthood tend to explore the impact of attachment on parenting capacity and relationships with adult partners (Collins, 1996; Cooper and colleagues, 2004; Dykas and Cassidy, 2011). Much less has been written about how the attachment style developed in childhood can become a significant factor in how an adult with dementia makes sense of their world. Baim and Morrison (2011) developed a framework which helps practitioners understand the nature of attachment in adults and the impact this may have on their children. It recognises that the more traumatic a person's history and the less opportunity they have had to reflect on it, the higher the likelihood this will interfere with parenting relationships and the wellbeing of their children. Helping adults reflect on past experiences may help them to recover and build resilience that will help sustain them through the lived experience of dementia. This is as valid a process for paid caregivers who require to be supported to understand both their own and others' attachment journeys.

Experience of attachment is with us throughout life and age remains the biggest risk factor in developing dementia. While not every older person develops dementia, a significant number of people are living with the disease and affected by its many changes to daily functioning. Bowlby's (1969) understanding that attachment is 'a lasting psychological connectedness between human beings' (p194) offers a theoretical backdrop to understand better the impact of dementia on people and on their families. That is the focus of this *Insight*.

## Living with dementia: the relevance of attachment

One of the main advances in preventative research in dementia over the last 10 years has been the growing body of evidence that brain disease can start as early as 30-40 years before the first signs of dementia appear. (Scottish Dementia Research Consortium, 2019; Alzheimer's Association International Conference, 2020). These issues of what Stern and colleagues (2019) refer to as 'brain maintenance' are the subject of ongoing study and are being linked to lifestyle considerations such as diet and exercise (Livingston and colleagues, 2017). So too, research into the long-term effects on

brain health for footballers who spent their younger years heading the ball (Russell and colleagues, 2019) raises important questions about key life events and the ensuing brain trauma that people may have experienced years before a diagnosis of dementia.

It is beyond the scope of this *Insight* to examine the potential links between Adverse Childhood Experiences (Walsh and colleagues, 2019) and the onset of dementia but it is evident that both areas of research share common threads. Here we shall limit our examination to how attachment contributes to our understanding of both the lived experience of people with dementia and the issues this raises for dementia support and care. As indicated earlier, secure attachments enable the development of meaningful relationships that are sustained over time and contribute to a sense of wellbeing and security. This suggests that securely attached people demonstrate more optimism about life; have more positive experiences of and with others; more positive self esteem and more effective coping strategies, all of which we recognise as elements of positive social functioning. While much of the research on brain reserve has focussed on the neurological functioning aspects (Valenzuela and Sashdev, 2006; Chapko, 2017;

Stern and colleagues, 2019) there are indicators that secure attachments and meaningful relationships may be protective factors against cognitive decline (Walsh and colleagues, 2019; Christie, 2020).

It has been suggested that ‘the special needs of this population call for a more sophisticated understanding of the caregiving process’ (Chen and colleagues, 2013 p333). In order to explore the complexities of that caregiving process, we shall examine key elements of the attachment process through the lens of dementia.

## **LOSS**

If ageing generally suggests increasing loss and vulnerability, then getting a diagnosis of, and living with dementia, represents multiple experiences of loss. Attachment is about proximity seeking to an individual who will provide a secure base. When someone experiences a sense of loss and vulnerability following a dementia diagnosis, this is one of the things they will do (Miesen, 1999). Research suggests that family caregivers who are able to tap into the ‘secure base’ narrative that was modelled for them by the parent who now requires support, can find the process of caregiving less stressful (Chen and colleagues, 2013). They are better able to reflect on the positives of

their own secure attachments and understand more compassionately the journey for the parent who is now living with dementia (Nelis, Clare and Whittaker 2014; Paulson and Bassett, 2016). Loss is experienced by both the person with dementia and their caregivers and this sense of loss can be particularly acute where the quality of pre-existing attachments was good (Cicirelli, 1995). Equally, it must be assumed that for the person with dementia for whom early attachments were not so secure the experience of loss is likely to be more complex for all concerned.

## **IDENTITY**

Central to what we understand about the importance of attachment in the lives of children is the extent to which this engenders feelings of safety and security and how this is intrinsically linked to identity and a sense of self. The internal working model developed out of early interactions and experiences can have a profound impact on the emerging sense of who we are as individuals, how we interact with others and how we respond to difficult or stressful situations (Daniel, Wassell and Gilligan, 2010; Walsh and colleagues, 2019). This has implications for a person living with dementia. Practitioners delivering dementia post-diagnostic support describe how much childhood

experiences and attachments affect people's ability to engage with support and care. For those people who find it difficult to engage, this can create a crisis at the very time that they may benefit most from support in and from the community to help them maintain their independence (Alzheimer Scotland, 2015).

Identity issues extend to the person who is further on in their dementia 'journey', helping us to understand some of the 'proximity seeking behaviours' (Bowlby, 1969) that are so often seen within hospital and care home settings. The person walking up and down the corridors seemingly searching for someone; the person who offers detailed explanation of why they need to get home for their tea on time; the person gravitating towards exits who rejects attempts by staff to engage them; can all be better understood if one is aware of their history of attachment. Similarly, having some understanding of the attachment patterns of the person may help explain the degree to which they feel driven to be in the company of others and could help

predict the extent to which they might benefit from social contacts. When taken together with how well they have maintained or lost cognitive function, this will provide insights into their ability to cope with difficult life events. (Chapko and colleagues, 2017).

Having good memories about a parent or an attachment figure has positive effects for us all. For people living with dementia, those deeply held and felt attachments help reduce stress, give comfort and create calm. It is also reasonable to assume that for those people with dementia who did not enjoy safe and secure attachments in their earlier life, their new world may become an increasingly bewildering and frightening space. 'Parent fixation' is a term used to

describe the re-emergence of the importance of a primary attachment figure, where people living with dementia believe their parent is still alive (when they are not) and want to be with them, usually at their original home. While people with higher levels of cognitive functioning are likely to show

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more overt attachment behaviour towards visiting relatives, as cognitive ability decreases, people may rely on more symbolic attachments for comfort and safety, such as their parents. (Meisen, 1999; Browne and Shlosberg, 2006). Symbolic attachment includes thoughts, memories and ‘talking to’ the attachment figure and is thought to increase feelings of comfort and safety, especially in residential settings where attachment needs might not be met.

There have been some small-scale studies that have applied attachment theory to interventions for people living with dementia. Recognising that the attachment figure might not be able to be present, the simulated presence of significant others was introduced in an NHS Assessment Unit in England in the form of recorded voices of relatives. Observations of behaviours afterwards included significant increases in positive responses, such as engagement, for people who were known to have a secure attachment with the relative whose voice was recorded and played back to them (Cheston and colleagues, 2007). The efficacy of this approach remains largely untested and a recent Cochrane review concluded that as yet there is insufficient evidence to support this as a therapeutic tool (Abraha and colleagues, 2020).

## **RESILIENCE**

Maintaining social connections demands complex interactions that need a variety of cognitive skills, so having a social life may help slow cognitive decline and be a preventative factor (James and colleagues, 2011). Conversely, at the time when people might most need strong social connections because they are facing cognitive decline and dementia, people with increasingly diminishing brain reserves may be more at risk of becoming isolated, fearful and lonely, all risk factors in developing dementia (Browne and Shlosberg, 2006).

Building resilience in adults with dementia is vital if they are to be enabled to maintain their place in the world for as long as possible. Christie describes resilience in this context as ‘the process of adaptation to hold on to a sense of self in the face of threats to identity’ (2020, p19). This can mean providing resources and supporting people to maintain connections and lifestyle choices even if they face the challenge of a retreat indoors that often comes with a dementia diagnosis. Up to 40% of people spend more than 80% of their time indoors following a diagnosis of dementia (Alzheimer’s Society, 2019). This process is often driven by loving partners, family or professionals wishing to protect the individual from a hostile or

seemingly risk filled world. A process described by Kate Swaffer (2015) as 'prescribed disengagement'.

### **FAMILY CARERS**

Family carers are recognised as the most important resource available for people living with dementia (World Health Organisation, 2017). As family carers are often adult children, in the same way that secure or insecure attachment affects people living with dementia, so too the nature of attachment to a parent directly affects the caring, and cared for, experience. So, where there is a secure attachment to a parent, it is perhaps not surprising that the evidence suggests this makes for a less stressful caring experience, one that is less likely to be defined as 'a burden' (Cooper and colleagues, 2008).

Other work suggests that secure attachment protects carers from the difficulties of caring – even if they are missing the parent or concerned or worried about them (Crispi and colleagues, 1997). Work on carer attachment also suggests that in dyads where both parties have experienced insecure attachments, this impacts on the ability of the carer to accurately report physical and psychological symptoms experienced both by the person with dementia and themselves

(Monin and colleagues, 2013). They are less attuned to their feelings and can miss valuable signs of stress and physical deterioration. As Shemmings (2000) suggests, 'From an attachment perspective, the ways in which interpersonal conflict in close relationships is resolved is associated with how individuals regulate feelings when under stress' (p40).

## **Implications for practice**

Workers engaging with families who are confronting a diagnosis of dementia would be well served by having a deeper understanding of the attachment histories of both the person with dementia and their carers. Many of the assessment processes used at present tend to have an emphasis on functional needs assessment and are less focussed on the psychosocial aspects of the life journeys of those involved. By understanding more fully the impact of past experiences, current issues can be better understood.

What Margaret's situation illustrates (below) is that a trauma-informed, holistic assessment serves not only as a useful aid to the selection of an appropriate residential placement, but also provides valuable insights for her future care management.

# MARGARET'S STORY

Margaret was born in 1931 in a small town near Dundee. In 1940, at the age of nine, she was evacuated to a fishing village on the Isle of Skye due to concerns for her safety. Although all of the children in her class were evacuated, none were placed close to her on Skye. We don't know all of her experiences during that time but we do know that she experienced an abrupt interruption to her secure family life and did not return home for two years. Now aged 89, Margaret has been struggling at home to cope with her advancing dementia and is now facing the prospect of admission to residential care. In planning for her future care, she is frightened of losing the safety and security that her own home has given her over the years. It's not just that residential care isn't her first choice, Margaret connects her fear of losing the security of her home where she has lived for 45 years with her memories of evacuation and separation from her mother at that time. She finds it difficult to trust that anyone wants the best for her when that might mean leaving her home where her memories of her mother are associated with her sense of safety and security. This information has only come to light following a full exploration of Margaret's personal history, including the attachments that were important to her. The social worker undertaking the assessment was able to explore with Margaret and her family how this disruption in her early life had influenced her as a partner and a parent, and make some evaluation of the significance of this proposed move. Her family's experience has been of a parent who has resisted change, gathered memorabilia of life events and changed little in her home over many years. Understanding the impact of this early trauma of evacuation provides valuable information to assist with the proposed transition to residential care.

Understanding attachment seeking behaviour helps those working in care homes to better understand and respond to expressions of loss and need. Just as is the case with good quality foster placements that understand the importance of a secure base to support care, so too good dementia care is based upon building relationships. It recognises that people with strong social connections built from secure attachments in early life, that they are able to maintain when they develop dementia, are best placed to live well (Magai and Cohen, 1998). Supporting people as their cognitive ability declines to stay connected to the people and environments that matter to them can be very positive, but regrettably this experience is not universal. It is crucial, therefore, that reminiscence tools are used with care and intelligence, taking account of family patterns and attachment histories (Sabir and colleagues, 2016).

At the time of writing this *Insight*, Scotland is enduring the COVID-19 global pandemic and

although some preliminary research has been undertaken (Wang and colleagues, 2020) we are a long way from understanding fully the impact on citizens with dementia, especially those living within care home settings. Given that this virus is particularly deadly within the elderly population, governments across the world have instituted

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a range of measures to attempt to protect this vulnerable group. Guidance in Scotland initially focussed on isolating residents from each other and reducing visitors to almost nil (Scottish Government, 2020a). As the trajectory of the virus has changed over time, so too has the guidance but as of September 2020,

although some communal activities and visiting has restarted, it is still greatly reduced from previous levels (Scottish Government, 2020b). Equally, within community settings, levels of contact and the range of services available are greatly reduced. While some research is now underway into the impact of such restrictions on those older adults with dementia,

it will be some time before any results are available (University of Edinburgh, 2020). For us to build on the best we have seen, and learn how to avoid the worst being repeated, understanding attachment in older people and their family carers may well be a useful contributor to the debate.

## Summary points for practice

- Understanding people's experience of attachment, as someone requiring support or as a family carer, is an important element in a person-centred approach to assessing need and planning for care.
- Supporting a person to reflect on their experience of attachment contributes to their capacity to build resilience and maintain their rights and choices through their dementia.
- Understanding attachment complements a rights-based approach by recognising the need for love and care throughout life.

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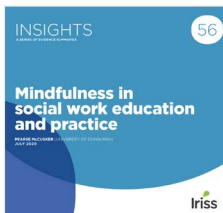
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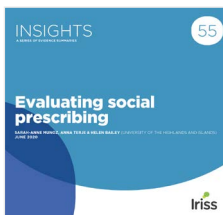
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